

# 'People say it is dangerous': Psychosocial consequences of Labelling People with Mild Hypertension – A Qualitative Study.

'Dizem que é o perigo': consequências psicossociais de rotular pessoas com hipertensão leve – um estudo qualitativo

*"Dicen que es el peligro": consecuencias psicossociales de etiquetar a las personas con hipertensión leve – un estudio cualitativo*

Janos Valery Gyuricza<sup>1</sup> , John Brodersen<sup>2</sup> , Lucas Bastos Marcondes Machado<sup>3</sup> , Ana Flávia Pires Lucas d'Oliveira<sup>1</sup> 

<sup>1</sup>Universidade de São Paulo, School of Medicine, Department of Preventive Medicine – São Paulo (SP), Brazil.

<sup>2</sup>Københavns Universitet, Center for Sundhed og Samfund, Forskningsenheden for Almen Praksis – København, Denmark.

<sup>3</sup>Universidade de São Paulo, School of Medicine, Family and Community Medicine Residency Program – São Paulo (SP), Brazil.

## Abstract

**Introduction:** Mild hypertension is a common asymptomatic condition present in people at low risk of future cardiovascular events. These people represent approximately two-thirds of those diagnosed with hypertension. The best available evidence does not support pharmacological treatment for mild hypertension to reduce cardiovascular mortality. Additionally, overdiagnosis 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 qualitative patient-oriented evidence that diagnosing hypertension has harmful consequences is observed. Therefore, evidence regarding the potential for unintended psychosocial effects of diagnosing mild hypertension is required. **Objective:** The aim of this study was to investigate if diagnosing low-risk people with mild hypertension has unintended psychosocial consequences. **Methods:** Eleven semi-structured single interviews and four focus groups were conducted in São Paulo, Brazil, among people diagnosed with mild hypertension without comorbidities. Informants were selected among the general population from a list of patients, a primary healthcare clinic, or a social network. The informants had a broad range of characteristics, including sex, age, education level, race/skin colour, and time from diagnosis. Data were subjected to qualitative thematic content analysis by three of the authors independently, followed by discussions, to generate categories and themes. **Results:** The informants confirmed that the hypertension diagnosis was a label for psychosomatic reactions to stress, medicalised illness experiences, and set a biographical milestone. 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 regarding work and leisure. Although informants had a broad range of characteristics, they shared similar stories, understandings, and labelling effects of the diagnosis. **Conclusion:** The diagnosis of hypertension is a significant event and affects daily life. Most of the impact is regarded as negative psychosocial consequences or harm; however, sometimes the impact might be ambiguous. Patients' explanatory models are key elements in understanding and changing the psychosocial consequences of the diagnosis, and healthcare providers must be aware of explanatory models and psychosocial consequences when evaluating blood pressure elevations.

**Keywords:** Medical overuse; Diagnostic errors; Hypertension; Models, biopsychosocial; Qualitative research.

### Corresponding author:

Janos Valery Gyuricza  
E-mail: jvgyuricza@usp.br

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## Resumo

**Introdução:** Hipertensão arterial leve é uma condição assintomática caracterizada por pressão arterial entre 14/9 e 16/10 mmHG e baixo risco de problemas cardiovasculares. É a condição de aproximadamente dois terços das pessoas diagnosticadas com alguma forma de hipertensão. A melhor evidência disponível não apoia o tratamento farmacológico desse grupo para a redução de mortalidade cardiovascular. Além disso, a sobredetecção de hipertensão ocorre e essa prática é apoiada por campanhas de conscientização ao público, rastreamento, acesso fácil ao teste e má prática clínica, que aumentam potencialmente o sobrediagnóstico. Poucas pesquisas qualitativas orientadas para os pacientes mostram que diagnosticar hipertensão pode ter também consequências negativas. Diante disso, são necessárias evidências sobre o potencial de efeitos psicossociais não esperados no diagnóstico de hipertensão. **Objetivo:** Investigar se o diagnóstico de pessoas de baixo risco com hipertensão leve tem consequências psicossociais indesejadas. **Métodos:** Onze entrevistas semiestruturadas e quatro grupos focais foram conduzidos em São Paulo, Brasil, com pessoas que relataram hipertensão arterial leve, sem comorbidades, com ou sem uso de medicação. Informantes foram selecionados da população geral por meio de lista de pacientes de unidades de atenção primária e também recrutados por redes sociais. Os participantes tiveram variedade em termos de sexo, idade, nível educacional, cor de pele e tempo de diagnóstico. Os dados foram submetidos à análise qualitativa de conteúdo temático por três dos autores independentemente, o que foi seguido de discussões para gerar categorias e temas. **Resultados:** os informantes confirmaram que o diagnóstico de hipertensão foi tomado como um rótulo para reações psicossomáticas ao estresse, medicalizou situações difíceis e causadoras de estresse, nomeando-as como doença, e foi um marco biográfico. Nós observamos consequências não intencionais do diagnóstico em uma ampla gama de dimensões psicossociais, por exemplo, medo de morte, doença e envelhecimento; pressão e controle por parte de pessoas próximas; e culpa, vergonha e ansiedade em relação ao trabalho e ao lazer. Apesar das diferentes características dos informantes, todos compartilharam histórias e sentimentos semelhantes relacionados ao rótulo. **Conclusão:** O diagnóstico de hipertensão é um evento significativo que afeta o dia a dia. A maior parte do impacto é considerada como consequências psicossociais negativas; porém, às vezes, o impacto pode ser ambíguo ou mesmo positivo. Os modelos explanatórios das pessoas são elementos-chave para entender e abordar as consequências psicossociais do diagnóstico, e profissionais de saúde e formuladores de políticas públicas devem estar atentos a esses potenciais consequências negativas na avaliação de risco/benefício das estratégias de diagnóstico desses casos.

**Palavras-chave:** Sobremedicalização; Erros de diagnóstico; Hipertensão; Modelos biopsicossociais; Pesquisa qualitativa.

## Resumen

**Introducción:** La hipertensión leve es una condición asintomática común presente en personas con bajo riesgo de eventos cardiovasculares futuros. Estas personas representan aproximadamente dos tercios de las personas diagnosticadas con hipertensión. La mejor evidencia disponible no respalda el tratamiento farmacológico de la hipertensión leve para reducir la mortalidad cardiovascular. Además, también se produce la sobre detección de hipertensión, y esta práctica está respaldada por campañas de concienciación pública, cribados, fácil acceso a las pruebas y mala práctica clínica, lo que aumenta el potencial de sobrediagnóstico. Además, se observa escasa evidencia cualitativa orientada al paciente de que el diagnóstico de hipertensión tiene consecuencias nocivas. Por lo tanto, se requiere evidencia con respecto al potencial de efectos psicossociales no deseados del diagnóstico de hipertensión leve. **Objetivo:** investigar si el diagnóstico de personas de bajo riesgo con hipertensión leve tiene consecuencias psicossociales no deseadas. **Métodos:** Se realizaron once entrevistas semiestruturadas y cuatro grupos focales en São Paulo, Brasil, entre personas diagnosticadas con hipertensión leve sin comorbilidades. Los informantes fueron seleccionados entre la población general de una lista de pacientes, de una clínica de atención primaria o de una red social. Los informantes tenían una amplia gama de características que incluían sexo, edad, nivel de educación, origen étnico, color de piel y tiempo desde el diagnóstico. Los datos fueron sometidos a un análisis de contenido temático cualitativo por tres de los autores de forma independiente, seguido de discusiones, para generar categorías y temas. **Resultados:** Los informantes confirmaron que el diagnóstico de hipertensión era una etiqueta para reacciones psicossomáticas al estrés, experiencias de enfermedad medicalizadas y marcaba un hito biográfico. Observamos consecuencias no deseadas del diagnóstico en una amplia gama de dimensiones psicossociales, por ejemplo, miedo a la muerte, discapacidades o envejecimiento; presión y control de otras personas significativas y culpa, vergüenza y ansiedad en relación con el trabajo y el ocio. Aunque los informantes tenían una amplia gama de características, compartían historias, entendimientos y efectos de etiquetado similares del diagnóstico. **Conclusión:** el diagnóstico de hipertensión es un evento significativo y afecta la vida diaria. La mayor parte del impacto se considera como consecuencias o daños psicossociales negativos; sin embargo, a veces el impacto puede ser ambiguo. Los modelos explicativos de los pacientes son elementos clave para comprender y cambiar las consecuencias psicossociales del diagnóstico, y los proveedores de atención médica deben conocer los modelos explicativos y las consecuencias psicossociales al evaluar las elevaciones de la presión arterial, comunicarse y tratar.

**Palabras clave:** Uso Excesivo de los servicios de salud; Hipertensión; Modelos biopsicossociales; Investigación cualitativa.

## INTRODUCTION

The psychosocial consequences of diagnosing people with hypertension were hypothesised approximately 70 years ago<sup>1</sup> and quantitatively investigated in the 1970s and 1980s. Alderman in 1990<sup>2</sup> observed a few studies that had suggested that diagnosing hypertension has psychological consequences. These effects were increasing illness, dependence on the healthcare system and absenteeism, and

worsening social relations and economic status.<sup>3-6</sup> The review also observed studies with conflicting results that had demonstrated minor impacts<sup>7,8</sup> and left space for debate. More recent quantitative studies have confirmed that a hypertension diagnosis affects people differently: the effects of having hypertension were most frequently measured on the basis of health-related quality of life or self-reported health, and a decrease in quality of life after the diagnosis of hypertension was confirmed.<sup>9-12</sup> However, as described by Trevisol and colleagues, the studies had been heterogeneous and not designed to assess the effects of the diagnosis.<sup>13</sup>

The literature on qualitative research on the effects of diagnosing hypertension has few examples and has indicated that people experience subjective changes regarding their self-conception and also multiple psychosocial consequences.<sup>14-16</sup> These studies were observed to have limitations to answer the research question of this study: two studies were conducted among hospitalised patients (those not at low risk) and could not separate the hypothesised psychosocial consequences of diagnosing hypertension from other potential sources,<sup>14,15</sup> whereas Sångren and colleagues conducted their study in Denmark (and not in a Brazilian context) to explore how primary healthcare patients experience and adapt to hypertension and share similarities with our research question.<sup>16</sup>

Currently, mild hypertension is defined as the levels between 140–160 mmHg systolic blood pressure and 90–100 mmHg diastolic blood pressure in people without established cardiovascular disease.<sup>17</sup> Most people diagnosed with mild hypertension are at low risk of future cardiovascular events<sup>18,19</sup> and do not benefit from a risk strategy based on pharmacological treatment for hypertension.<sup>20</sup> Nevertheless, people at low risk are diagnosed and treated as hypertensive according to present definitions and guidelines, jumping quickly or never been at non-pharmacological approach and constitute the bulk of the population under pharmacological treatment.<sup>21</sup> As a result, it is reasonable to affirm that most people labelled as mild hypertensive are overdiagnosed.<sup>22</sup>

Overdiagnosis unnecessarily transforms people into patients by identifying problems that were never going to cause harm or by (over)medicalising ordinary life experiences through expanded definitions of disease.<sup>22</sup> The overdiagnosis of hypertension is primarily derived from its overdefinition, considering the current low thresholds used to dichotomize a risk factor described on a continuous variable. Most of the cardiovascular events occur in people without blood pressure levels greater than the diagnostic threshold for mild hypertension, which supports that the present definition of hypertension alone is a poor predictor of cardiovascular events.<sup>23</sup> The lower the risk, the lower the individual benefit of treatment, and greater numbers of people would have to be treated for a population benefit.

Another impetus for overdiagnosis is overdetection of hypertension, which is supported by public awareness campaigns, screening policies, easy access to testing, and poor clinical practice. Overdiagnosis leads to overtreatment, which occurs when the best available evidence demonstrates that a treatment provides no net benefit for the diagnosed condition or, in other words, that the harms outweigh the benefits.

In the literature, the potential benefits of diagnosing hypertension have been far more investigated and reported compared with the potential harms. As evidenced by the Cochrane review,<sup>20</sup> studies did not include people with mild hypertension, and consequently, it is uncertain whether this group of people benefit or not from the diagnosis. Nevertheless, diagnosed people can suffer harms that are not restricted to pharmacological side effects. One of these harms might be the psychosocial consequences of labelling.

The psychosocial consequences of the labelling can be better understood by also observing the explanatory model (EM) of disease and illness. EMs are the notions individuals and groups have of a certain topic and describe sickness as the union of illness and disease. The distinction between illness and

disease has been widely described by anthropological and sociological studies.<sup>24</sup> Illness is the EM for a person who is ill, whereas disease is the medical EM; nevertheless, both models interact and are culturally determined.<sup>25</sup> Kleinman's EMs were used to describe a patient's understanding of the causes, symptoms, treatments, and prognosis of hypertension,<sup>26,27</sup> but have not yet been used to understand the psychosocial consequences of labelling. Qualitative studies using EM have described similar EM of hypertension across different cultures.<sup>28,29</sup> Therefore, the aim of this study was to investigate the EM of hypertension and the unintended psychosocial consequences of diagnosing mild hypertension in people without comorbidities in a Brazilian context.

## METHODS

### Data collection

We recruited the informants *ad hoc* for single and group interviews from public primary healthcare services [Unidade Básica de Saúde (UBS)] in São Paulo western region and using social media and the authors' social contacts. The two UBS were conveniently selected among those that the authors had previous clinical work. The informants were selected purposefully to obtain a wide range of experiences and variety regarding age, time from diagnosis, education level, gender, and race/skin colour, and were not patients of the authors.

Informants selected from the UBS were identified in the lists of people diagnosed with hypertension. In Brazilian UBS, it is required from the community healthcare workers [agentes comunitários de saúde (ACS)] to keep a list of patients with hypertension (and with other conditions such as diabetes or bedridden). We asked the ACS to pick in the list and invite the informants for our interviews. Informants selected from social media responded to an invitation posted on Facebook in our own profiles. Our social connections suggested a few of the informants. We had informants using both public and private healthcare services.

A telephonic interview was conducted to identify the inclusion and exclusion criteria among eligible informants from these different sources. We selected Informants raised in Brazil aged 18 years or older who self-reported a confirmed diagnosis of hypertension by a physician, no other cardiovascular conditions, and no other chronic or disabling conditions. We did not assess the informants' clinical files nor measured the informants' blood pressure. None of the eligible informants we contacted via telephone refused to participate.

We adopted a qualitative phenomenological methodology to achieve our aim. The psychosocial dimensions we focused on here include bodily perceptions; ageing; death; psychological aspects; interpersonal relations (family, friends, and colleagues); and broader social relations such as work and employment, leisure, citizenship, and political engagement and economics. All these relevant psychosocial aspects of everyday life are in accordance with patient-centred clinical methods and Engel's biopsychosocial model<sup>30-32</sup>.

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 was not fixed and could evolve from one interview to the next, depending on the information we obtained from the interviews, and comprised topics only for the interviewer. The guide included the following psychosocial categories and subcategories:

- EM of hypertension: what, why, when, where, and how?
- Psychological effects: body perception and feelings about ageing, death, and disease.

- Social effect: ethics, relations with others (family, friends, and others), public spaces, employment, citizenship, and economy.

The informants were encouraged to openly discuss their knowledge and experiences of being diagnosed with hypertension, and we 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. We 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.

We decided data saturation had been achieved when we agreed that nothing new was being revealed in additional interviews, and we had obtained a sufficient amount of material to achieve our objective.<sup>33</sup> After the single interviews, we conducted the focus groups interviews. Digital technology was used to record the audio of all interviews, and then the audio was transcribed verbatim.

No patients or members of the public participated in the planning or conduction of the study. All informants provided their informed consent, and the study was approved by the necessary ethical committee, registered with CAAE 54699716.0.0000.0065. The data sets used and/or analysed during the current study are available from the corresponding author on reasonable request.

## Data analysis

We listened to the audio files and read each interview many times until impregnation to explore the results. From the perspective of the systemic theory and Kleinman's Ems<sup>32</sup> and Engel's psychosocial proposal, we analysed the data by using thematic content analysis.<sup>34</sup> 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 considered that informants built their conceptions from their relationships with doctors, family, media, coworkers, and friends, and that they also create and recreate these conceptions and behaviours historically in social life.

Three of the authors of this study analysed all the interviews and focus groups transcriptions and agreed regarding the coding structure and coding each transcript separately. When these authors' interpretations differed, quotes representing units of meaning (codes) were compared and discussed repeatedly. Codes were grouped to generate categories. The authors compared the codes with the original text to ensure that the codes were rooted in the material. Those categories were discussed and related to the theoretical framework until the authors 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. The software NVivo® was used to manage data.

## RESULTS

We 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. There was no other person during the interviews besides the informants and the researchers. The duration of each interview was 30–90 min. After the single interviews, we conducted four focus group interviews (Table 2) facilitated by two researchers in an easily accessible location: either the UBS or one of the informant's home. Focus groups comprised informants with similar characteristics regarding sex and education level and lasted for 90 min. Tables 1 and 2 present the participants and use fictitious names.

**Table 1.** Single interviews.

Order	Person	Sex	Age	Race/skin colour	Education (years completed)	Time since diagnosis (years)
1	Iago	Male	30	White	18	4
2	Julieta	Female	21	Black	9	4 months
3	Othello	Male	36	White	19	3
4	Jessica	Female	35	Mixed	8	1 month
5	Desdemona	Female	36	White	16	4
6	Horacio	Male	46	White	11	1.5
7	Cordelia	Female	44	White	20	9
8	Ophelia	Female	64	White	11	7
9	Viola	Female	65	White	11	22
10	Gertrudes	Female	64	Mixed	11	15 years
11	Romeu	Male	44	Mixed	18	8 years

**Table 2.** Focus groups interviews.

Group	Person	Sex	Age	Race/skin colour	Education	Time since diagnosis (years completed)	Local
1	Livia	Female	42	Mixed	11	12	UBS
	Cecilia	Female	43	White	15	2	
	Placida	Female	50	Black	15	15	
2	Angela	Female	57	Mixed	8	17	UBS
	Helena	Female	65	Mixed	11	30	
	Eugenia	Female	74	White	5	20	
3	Bras	Male	43	Black	11	3	UBS
	Quincas	Male	65	Mixed	8	8	
	Camilo	Male	65	White	Illiterate	15	
4	Rita	Female	51	Mixed	16	13	Home
	Sofia	Female	55	White	11	3	
	Virgilia	Female	56	White	16	1	

UBS: Unidade básica de saúde (the Brazilian public primary healthcare service)

The study population had a broad range of sociodemographic characteristics, and the sample included a couple of health professionals. We included people – regardless of sex – aged 21–74 years who had been living with the diagnosis of hypertension for 1 month to 30 years. The informants could be



illiterate or have a low, medium, or high level of education, and had different race/skin colour. The sample also varied regarding the utilisation of the public or private health services.

In the first content analysis, we identified 42 categories. After discussions between all the authors, these categories were merged into 2 main themes, 7 subthemes, and 14 sub-subthemes. The two main themes were patients' EM of hypertension and psychosocial consequences. For details regarding the subthemes and sub-subthemes, see Table 3.

**Table 3.** Patients' explanatory model of hypertension and psychosocial consequences of the diagnosis and their subthemes and sub-subthemes.

Theme	Subtheme	Sub-subtheme
	What is hypertension?	
Patients' explanatory models of 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
		Family
Relational and social consequences	Friends	
	Work	

The focus group interviews confirmed the findings of the individual interviews. Patients described a wide range of patients' EM and psychosocial consequences. We first treated patients' EM and psychosocial consequences separately and provided quotes demonstrating their content. Next, we demonstrated how patients' EM and psychosocial consequences may be related and describe the resulting conceptual model.

### Patients' explanatory models of hypertension

In the interviews, hypertension was reported as a chronic disease/condition and as 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.

### *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 trying to describe 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 similar to Jessica, who described hypertension as 'harmful to her health'.

Othello stated:

What the fuck! Now, I am a chronic patient.

None of the informants had received a hypertension diagnosis during an opportunistic or screening measure. Only one of the informants related a thorough investigation with several measurements of the blood pressure inside and outside the medical office. The rest of the participants received a diagnosis after a single measurement. 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.

### *Intertwined relationship with symptoms*

Patients provided two descriptions for symptoms: no symptoms related to blood pressure and symptoms when their blood pressure was high. The patients identified several symptoms and emotional factors as a cause and/or as a consequence of hypertension. Informants justified blood pressure elevation symptoms as related to stressful events. Additionally, 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.

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 intertwining:

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!

#### 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, I just felt headache.

#### 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.

#### *Causes of hypertension*

Patients reported modifiable and non-modifiable 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 non-modifiable cause under the sub-subtheme 'bad genes'.

#### 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.

Gertrude stated:

It is up to me to control my high blood pressure: less salt, no smoking and no drinking. Everyone knows that.

#### Bad genes

Additionally, the non-modifiable 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 am used to 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.

## **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 pharmacological and non-pharmacological measures and expressed also 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 pharmacological treatment established a disease that named illness experience and was considered the most critical and effective intervention to avoid negative outcomes, although non-pharmacological measures, for example, stress control and change in lifestyle and habits, were also recognised and valued.

Juliet: 'I have seen a lot of people with blood pressure problems, some even died'.

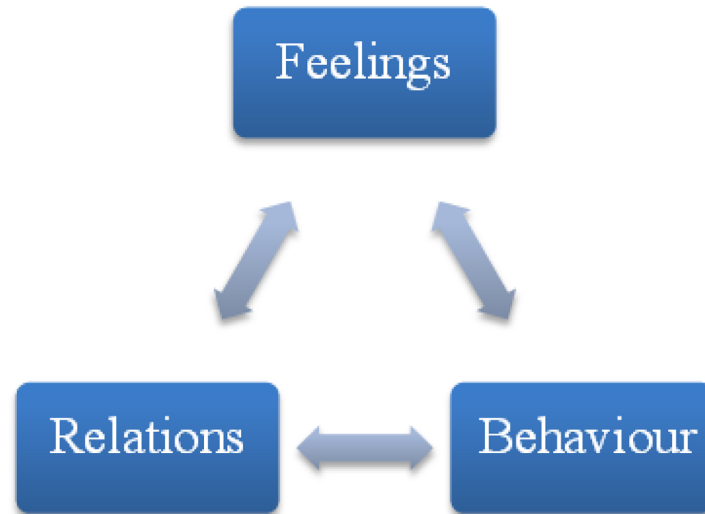
Ophelia: 'High blood pressure leads to, as I heard a doctor on TV a few days ago, leads to a stroke. If I can eat with less salt, be physically active (...) if I can take these precautions, I will live happily for the rest of my life if God wills. I am not afraid. Frankly, the only thing that I am afraid of is a stroke—God, do not give me that!'

## **Psychosocial consequences of the diagnosis of hypertension**

We divided the psychosocial consequences into three, interconnected analytical dimensions: feelings (intrasubjective), behaviours (understood by the informant as individual choice), and intersubjective and social relationships – a triologue (Figure 1).

The diagnosis was perceived as a threat and triggered psychological reactions. These feelings had a direct effect on personal relations with family, friends, and at work and motivated irregular changes in behaviour (adherence to pharmacological 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, who said that for him hypertension 'was nothing', 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.



**Figure 1.** Triadogue of the three dimensions of psychosocial consequences.

### *Emotional consequences*

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

Fear: risk of dying or becoming ill

The major psychological 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, they thought they should control. 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.

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.

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.

## **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 pharmacological 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.

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.

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.

Some informants took treatment for granted, other informants doubted if 'the need' for medication was genuine, and others used medication successfully according to their patients' 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 of lifestyle changes.

### *Relational and social consequences*

The severe outcomes attributed to hypertension affected personal relations when the informants described how 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 patients' EM. Changes in lifestyle were seen as 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 how their social relations control their behaviour in similar terms.

Iago: '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'.

Othello: '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'.

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.

There were very few reports regarding the cost of treatment related to transport, medicine, exams, or cost of professionals.

## **DISCUSSION**

### **Major findings**

For the informants, hypertension was a chronic, deadly, and silent or symptomatic disease/condition related to habits, lifestyle, and genes, and hypertension could trigger acute symptomatic exacerbations

related to stress. Additionally, the informants seemed to miss the biomedical conceptualisation and diagnostic criteria for hypertension. This is not something unexpected in a context where public awareness and individual care is more valued than primary prevention population strategies, doing the opposite of what Geoffrey Rose suggested<sup>35-37</sup> and strengthening Tudor Hart's Inverse Care Law.<sup>38</sup>

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 on, death was lurking and dressed as hypertension. Moreover, our results showed that the EMs 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, highly related to the elements they have got from doctors and awareness campaigns on hypertension.

People measured their blood pressure during stressful situations, and the acute symptomatic events related to stress (emotional and somatic reactions) were then attributed to the blood pressure elevation. In this manner, the diagnosis made previously healthy people ill, transforming a risk factor in the cause and consequence of stress-related symptoms and creating an illness experience. Hypertension is considered by medical science as mostly an asymptomatic risk factor; hence, the diagnosis of hypertension in this study can be described as provoking illness without subjacent disease.

In the web of events around the diagnosis of hypertension, the medical encounter is only one anchor point. The illness process begins with personal awareness of a change in body feeling and continues with the labelling of the sufferer. The diagnosis of hypertension named the psychosomatic reactions to stress and overmedicalised 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.<sup>25,39</sup> 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 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, blurring the pressure of social conditions and giving the person a 'magic pill' to treat it.

In many cases, the medical diagnosis is a benefit because the illness is named, symptoms are explained, and effective treatment may now be possible;<sup>40</sup> unfortunately, this might not be the case with mild hypertension.

In spite of no clear benefit in the pharmacological treatment of mild hypertension,<sup>20</sup> recent changes in guidelines with lower treatment thresholds mean that more people will be overdiagnosed and overtreated<sup>41,42</sup>. Furthermore, 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 the label of hypertension; without a clear benefit: at the individual level, the risk factor becomes a disease. And the psychosocial consequences of labelling hypertension become a public health issue.

In our findings, many (if not all) of our informants might have had a false-positive diagnosis or a misdiagnosis, maybe the result of poor clinical practice. The technique used to measure blood pressure is detailed (requires more than 10 steps), more than one measurement in a few days are needed to



establish the diagnosis of hypertension according to most guidelines.<sup>43-45</sup> Errors in the measurement of blood pressure and psychological stress in the moment of the procedure can lead, among other factors, to misdiagnosis.<sup>43,44</sup> Many of the participants of the study received their diagnosis after a single blood pressure measurement, often in stressful situations. Only one informant was investigated with several measurements, inside and outside the office. This suggests that some of the participants might have been misdiagnosed as a result of poor clinical practice. Although we expected to aim at those with mild hypertension, we did not make this distinction within our informants. Nevertheless, it is reasonable to assume that among healthy people that carry only the label of being hypertensive, the labelling effect might be the same, regardless of the blood pressure level.

Additionally, many people – lay and healthcare providers – use the word hypertension (and its correlates) with different meanings at different times. In the Brazilian context, words related to high blood pressure have many meanings and uses that overlap regarding pressure and tension: blood pressure and psychological tension are not easily untangled because they are highly connected. This might explain the phenomenon of the intertwined relation with symptoms. 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.<sup>46-48</sup> Acute symptomatic events and the medical diagnosis are experiences that overlap because of the relation with blood pressure elevation. The diagnosis is a crucial moment which triggers reactions that might be beneficial or harmful.<sup>40</sup> Our results confirmed qualitative results in the literature demonstrating similarities in the EM of hypertension in different settings and 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.<sup>16</sup> Many of the accounts from the Brazilian informants shared similar interpretations compared with Danish informants.<sup>16</sup> This relevant finding suggests external validity because both cultures are geographically opposite in the Western world. A systematic review of Marshal and colleagues also confirmed that among different cultures the diagnosis is frequently established during major life events.<sup>49</sup>

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 argument might be that the diagnosis (and consequently fear) can act as motivation to adopt a healthy lifestyle,<sup>40</sup> helping people make 'better choices'. This phenomenon sometimes occurred, but the duration did not seem to last. Moreover, these 'better choices' 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. Hence, for example, 'healthy food' depends on abundance, price, access, and many other attributes beyond individual choices, as the informants conceived.

Our findings support the hypothesis that the diagnosis of hypertension can be referred to as a label in the socio-anthropological sense. Patients do not self-attach labels on their own, but are labelled by healthcare providers. The diagnosed person accepted a discrediting attribute (the diagnostic label) and acted and reacted accordingly to the stereotype. Medical science has the power to set the standards of normality, articulating what it is to be a normal person and to behave in a normal manner; hence, the healthcare system creates and attaches the label. Social relations supported the label with control and prejudice from others, which acted to create stigma.<sup>50</sup>

## Strength and limitations

We interviewed only a few residents of São Paulo, and this factor could represent a narrow source of relevant experiences. However, because of the demographic history of Brazil, this number does not limit the broadness of cultural viewpoints. Nevertheless, we recommend this hypothesis be tested by similar studies in different settings.

## CONCLUSION

Brazilian patients' EMs share similarities with other populations. Diagnosing mild hypertension in the Brazilian context has shown to lead to negative psychosocial consequences, related to the patient's EM. These consequences are mostly regarded as harms to well-being; these are the effects of a label. Moreover, the diagnosis names illness experiences in people that do not benefit from medical treatment, exposing them to a higher risk of collateral effects and overmedicalisation.

The results have implications for clinical practice, as to improve their clinical skills, health professionals must be aware of the effects of context on blood pressure and the psychosocial consequences of labelling hypertension. It also has implications for public health and primary prevention of cardiovascular disease. In high-risk strategy settings, very low thresholds might have great overdiagnosis negative consequences, unbalancing the benefit/harm relationship to the side of harms. The results of this study support the development of further research to address the effects of labelling in a quantitative manner.

## CONFLICT OF INTERESTS

Nothing to declare.

## AUTHORS' CONTRIBUTIONS

JVG: Conceptualization, Data curation, Formal analysis, Funding acquisition, Investigation, Methodology, Project administration, Resources, Writing – original draft, Writing – review & editing. JB: Conceptualization, Formal analysis, Methodology, Supervision, Writing – review & editing. LBMM: Data curation, Formal analysis, Investigation, Writing – original draft, Writing – review & editing. AFPLO: Conceptualization, Data curation, Formal analysis, Funding acquisition, Supervision, Methodology, Writing – review & editing

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