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#### Title of the thesis

Cooperation and Resistance toward medical treatment in Hypertensive patients who require lifestyle changes.

Exploration of patient's schemas and personal constructs

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#### Introduction

Arterial Hypertension (HT) is a chronic disease characterised by an elevation in arterial blood pressure beyond normal levels, which leads to an increase in the risk for several cardiovascular diseases (Passalacqua, 2005). In Chile it's one of the most relevant epidemiological problems, with a prevalence of over 20% (although only 5% have very high<sup>1</sup> HT), directly relating to the most frequent causes of death and being one of the main causes of lost Years of Healthy Life (MINSAL, 2009-2010).

Worldwide efforts in controlling and preventing this disease have produced an integral treatment plan that includes medication and diet plus exercise routine changes, with an emphasis in prevention and promotion of a healthy lifestyle (Linden & Moseley, 2006). Besides, several researchers recognise the usefulness of psychosocial strategies such as depression and stress treatment programs for improving adherence (Blumenthal et al, 2002; Sperry, 2006).

Despite the proven efficacy of regular treatment, research indicates that hypertension is resistant to treatment (Reyes & Atalah, 2006), with recent Chilean and international data suggesting that that less than 30% of all treated patients reach a normal blood pressure level (Mendoza, Muñoz, Merino & Barriga, 2006; WHO, 2003). To make matters worse, a recent Chilean National Health Survey showed that only 65% of all hypertensive patients know their condition, 37% have pharmacological treatment and only 17% had reached normal blood pressure levels (MINSAL, 2009-2010).

Low treatment adherence has been pointed as the main reason for regular treatment's low efficacy (WHO, 2003). This finding has motivated numerous research projects to focus their efforts in understanding and improving patients' adherence to treatment, not only in hypertension, but also across other chronic conditions (WHO, 2003). This can be related to the fact that in these illness the patient is required to make important long term lifestyle and behavioural changes (Orueta, 2005), and also to the fact that in chronic illness the patient is also the main care-giver (Creer, Holroyd, Glasgow & Smith, 2004), increasing the chance for non adherence. Specifically in hypertension, adherence rates are poor (30–60%) for medication taking and lower for diet and exercise changes (Martin, Williams, Haskard, &

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<sup>&</sup>lt;sup>1</sup> HT is diagnosed if blood pressure measures are over 140 / 90, and it can be asymptomatic; very high blood pressure is diagnosed if those levels rise over 180 / 110.

Dimatteo, 2005). Also, half of the patients stop taking their medication during the first year of their treatment (Ingaramo et al, 2005; Jones, Hyland, Hanney & Erwin, 2004), which is similar for other chronic diseases like type II diabetes. In psychotherapy, dropout rates also hover around 30–60% and 50% of all psychotherapy clients don't comply with their homework assignments (Levensky, 2006).

Behavioral medicine and health psychology have improved the understanding of the adherence problem and determinants, conceptualizing it as a complex process determined by patient, health professional, health system, illness and therapy factors, such as patient self-efficacy, problem awareness and information about the illness; treatment complexity and dosage; visibility of symptoms, etc. (Meichenbaum & Turk, 1991, World Health Organization [WHO], 2003).

Although adherence research has been very productive, it has not been able to predict patients' adherence behaviour, only estimating their intention to adhere (Christensen, 2004). Also, interventions based on this research are generally complex and have moderate effects (Haynes, Yao, & Degani, 2005). This can be explained by some shortcomings: (a) it has been almost exclusively used quantitative and correlational methodologies; (b) the few existing qualitative studies are made from a social psychology or anthropology perspective, which can be complemented from a clinical psychology viewpoint; (c) almost all theoretical models and intervention strategies for improving adherence are from a psycho-education and cognitive-behavioural background, measuring psychological variables via explicit self-report measures and neglecting underlying, implicit affective meanings (Creer, Holroyd, Glasgow, & Smith, 2004; Haynes et al., 2005; van Geelen, 2010). Regarding future challenges, recent developments emphasise the importance of considering the interaction between context and patient variables (Christensen, 2000), the need for patients to have a very active collaboration in the treatment (Creer et al, 2004), and the relevance of addressing patients' motivation process (Prochaska & Diclemente, 1992; Miller & Rollnick, 1999).

How to address these limitations and future challenges? First: because medical treatment adherence for chronic illness requires change in patient behaviour, and behaviour changing principles may be used for understanding that process (Willey, 1999), the present dissertation aims to complement adherence theory and research

with concepts developed in clinical psychology and psychotherapy research. Second: the methodology includes the use of qualitative techniques. Third: it has an integrative theoretical background rooted in psychodynamic, constructivist, humanistic and interactional perspectives. Fourth: it considers the interaction of patient and context (doctor-patient relation) variables. Fifth: it explores patient's motivation process from their own perspective, including implicit and explicit constructs and schemas.

In order to do this, the non adherence problem is understood as a problem of resistance to change, defined as wanting to change but not cooperating fully with the treatment (Arkowitz, 2002). Theoretically, this study proposes two changes regarding the standard conceptualisation of resistant or non adherent behaviour (Bosworth, Oddone, & Weinberger, 2006):

- Instead of understanding resistance as an individual phenomenon of the patient, viewing it as a relational phenomenon that cannot be analysed or understood independently from the treatment context and the interaction with the caregivers (L. Beutler, Rocco, & Moleiro, 2001; Christensen, 2000).
- Instead of considering adherence the only positive option, understanding nonadherence as an adaptive and valuable response, coherent with patient's existing constructions of reality (implicit or explicit) and his available psychological resources and possibilities (Arkowitz, 2002; Ecker & Hulley, 1996; Engle & Holiman, 2002).

This conceptualisation of resistance or nonadherence will be made in the broader context of a constructivist and dialogical understanding of the self, explained in section 2.5 (Frankel & Levitt, 2006; Hermans, 2008).

Accordingly, the present dissertation explores such ambivalence in non adherent hypertensive patients. To express it in simple terms, the question that motivated this study was the following: why people who are ill, and decide (or at least agree) to enter a medical treatment program to improve their wellbeing, do not adhere to it? In this context, the present dissertation aims to contribute to medical and health psychology research questions from a clinical psychology perspective, using

concepts and research findings developed in a psychotherapeutic context that complement the usual theoretical perspectives used by most adherence researchers.

This dissertation's main research question is: How is patients' cooperation or resistance to the medical treatment of hypertension related to patients' and caregivers' relational patterns, patients' personality, their implicit pro and anti adherence schemas and positions, and the way they have experienced the treatment process?

## **Objectives**

The main objective of this study is to explore, describe and relate hypertensive patients' adherence to their medical treatment, to their implicit constructs and schemas regarding cooperating or resisting the treatment, their interactions with the caregivers, their experiences about their treatment and illness over time, and elements of their personality structure.

In table 1 we present the original specific objectives, plus the modified ones that we defined for stage two of the project, after analysing stage 1's results:

Table 1: Specific Objectives: Stage 1 and Stage 2

Theme / Factor	Objectives Stage 1	Objectives Stage 2
Patient's	Describe patients'	Describe in the sample the
Personality	personality structure.	four patient prototypes
		identified in stage one (see
		Appendix 7), with their
		specific markers.
Patient- Caregiver interaction	Describe caregiver- patient interactional patterns.	Describe how patients experience and signify the interaction with their
Interaction	patterns.	caregivers.
Schemas and constructs regarding cooperating or resisting treatment	Explore and describe patients' personal constructs and schemas regarding their adhering and not adhering to medical treatment.	Describe patients' implicit and explicit voices or positions for not adhering to medical treatment.
Experience of	Explore and	- Describe patients' reactions
treatment	describe how	to the Hypertension

process	patients' experience and signify the treatment process over time.	diagnosis Describe patients' account of important events in the treatment process.
Factors related to patients' adherence	Identify relations between previous factors and patients' adherence.	Identify relations between previous factors and patients' adherence.

#### **Directive Questions**

## Regarding patients' anti and pro adherence implicit positions and schemas:

- When the patients' adhere and don't adhere to treatment, what do they want to preserve or achieve? What personal values are at stake?
- Does the adherent and not adherent behaviour relate to important aspects of patients' sense of identity? If so, which ones?
- What patients' constructions and schemas are coherent with their adherent and non adherent behaviour (pro and anti symptom positions)?
- What construction exists that makes not adhering more important than adhering to medical treatment?
  - What does the resistant behaviour do for the patient that is valued or needed in the patient's world?
  - To what problem is non adherence a solution or an attempt at a solution?
  - What are the unwelcome or dreaded consequences that would result from adhering to treatment? What would happen if, in the contexts that trigger non adherent behaviour, the patient would adhere to medical treatment?
  - If the non adherent behaviour had a goal or aim, maybe unconscious / implicit but important for the patient, what would it be?

#### Regarding patients' personality structure

 What psychological functions differentiate adherent and non adherent patients? • What character and personality traits differentiate adherent and non adherent patients?

## Regarding doctor-patient interaction patterns

- What is the interpersonal meaning of patients' adherent or non adherent behaviour (from the patients' perspective)?
- Is doctor-patient interaction symmetrical or complementary?
- What interpersonal patterns characterise doctors' and patient's interaction?
- How can doctor-patient interaction be characterised in terms of activity / passivity, control / submission and warmth / hostility?

## Regarding evolution and change in the treatment process:

- What initial expectations do patients have about their illness and treatment?
- Do patients identify treatment features that facilitate or present obstacles for their motivation and active cooperation in the treatment process? Which ones?
- Do patients identify changes in their motivation and active cooperation during treatment process? How do these changes develop?
- Do patients recognise turning points in the treatment process? How do they describe them?

## **Empirical and Theoretical Background**

This brief revision of relevant empirical and theoretical data will start by presenting background information about chronic illness, followed by specific data about hypertension, its aetiology and treatment. Then, some findings regarding adherence to medical treatment will be presented, continuing with theoretical models used in psychotherapy for understanding patients' resistance. Finally an explanation of this dissertation's specific theoretical framework will be offered.

#### Chronic Illness

The World Health Organization's Adherence Project defines chronic illnesses as "diseases which have one or more of the following characteristics: they are permanent, leave residual disability, are caused by nonreversible pathological alteration, require special training of the patient for rehabilitation, or may be expected to require a long period of supervision, observation or care" (WHO, 2003, p. 4). An important difference with acute diseases is that they require lifestyle changes as well as an adjustment period to the physical, psychological and social changes demanded by the disease or its treatment (Avendaño Monje & Barra Almagiá, 2008). Chile, as well as other developing countries, is living an epidemiological transition period, from infectious to chronic diseases, which are now responsible for three of the four main causes of death around the world: cardiovascular diseases, cancer, and chronic respiratory illness (MINSAL, 2009-2010; World Health Organization, 2003).

Because of its increasing prevalence, Health psychology has focused on the differences between acute and chronic illness, from the patients' and medical system's experience. Some of the findings indicate that: (a) the diagnosis is difficult to accept for patients, who often expect a "magical cure" and shop around seeking it from treatment to treatment; (b) when patients accept their condition, they often feel helpless and sometimes stay in a denial phase, instead of using the self-care skills required to control their condition; (c) their symptoms fluctuate constantly, which produces uncertainty in patients and the medical team, related to the fact that the perception of patients' own health depends on their experience of somatic changes, as well as cognitive, affective and physical functioning; (d) caregiver's uncertainty doesn't communicate to patients, who start treatment convinced that if they follow the

prescriptions, their chronic condition will be controlled (Brownlee, Leventhal & Leventhal, 2000; Creer et al, 2004).

Another important difference with acute conditions is that in chronic illness the patient is his main caregiver, not the medical system (Creer et al, 2004). This complicates treatment, because on one hand the medical system forgets the importance of patients' participation and cooperation, and on the other hand patients often prefer to surrender their responsibility completely to their caregivers. This fact, added to the numerous lifestyle changes required, could be related to lower adherence rates in chronic illness (Creer et al, 2004).

An interesting development that aims to address this issue is the *Collaborative management* model (Von Korff, Gruman, Schaefer, Curry & Wagner, 1997), which includes collaborative definitions of problems, goal setting, and treatment planning, training in self-management, support and follow-up. This view challenges the traditional teaching method in medicine, which is based on an inpatient setting, with the patient subjected to the care and decisions of the medical staff, assuming a passive stance. Although a great number of diseases are treated this way, it doesn't apply to chronic illness (Facchini, 2004).

## Hipertension

Hypertension (HT), diagnosed when recurrent blood pressure is over 140 / 90 for adults (NIH, 2003; MINSAL, 2009-2010), is classified as essential when there is no identifiable medical cause (95% of all cases), or secondary (only in 5% of all cases), when there is one. It increases the risk of ischemic heart disease 3- to 4-fold, of overall cardiovascular risk by 2- to 3-fold, and of stroke between 3 to 8-fold (WHO, 2003), being responsible of 62% of cerebrovascular disease and 49% of ischemic heart disease, all of which makes HT the number one attributable risk factor for death throughout the world (Lenfant, Chobanian, Jones, & Roccella, 2003).

Worldwide prevention and treatment efforts have generated results that, although improved, are still lacking. Despite increases in public awareness (from 51% to 70%, between 1976 and 2000), percentage of patients treated (31% to 59%), percentage of patients with high blood pressure successfully controlled (10% to 34%, all data from U.S.A. population) (Lenfant et al., 2003) and the availability of effective

treatments, in most countries more than 75% of all treated patients fail to achieve optimum blood pressure. For example only 7% achieve optimum blood pressure in the United Kingdom and 4,5% in Venezuela, being poor adherence the main cause of treatment failure (WHO, 2003).

Regarding its aetiology, despite the fact that in 90–95% of all cases it's impossible to determine the specific causes of the pressure increase (Gatchel & Oordt, 2003), it has been associated to several risk factors which can be grouped in biological factors (genetic predisposition, obesity, aging, etc...), diet and exercise habits (high sodium intake, low potassium and calcium intake, sedentary lifestyle, alcohol intake, etc...), psychological factors and socio-cultural factors (Carels, Blumenthal & Sherwood, 2000; Carretero & Oparil, 2000; Dressler, Bindon & Neggers, 1998; Nezu, Maguth, Geller & Weiner, 2004).

Among psychological factors associated with HT and cardiovascular conditions, research has found that acute and chronic stress, anxiety, negative emotions, repressive coping strategies, anger inhibition, depression, low social support and defensiveness are risk factors or can directly trigger cardiovascular problems (Carels, Blumenthal & Sherwood, 2000; Denollet, Martens, Niklicek, Conraads & Gelder, 2008; Nezu, Maguth, Geller & Weiner, 2004).

Other researchers, from a broader perspective have emphasised socio-cultural variables such as social stressors, economic status, the "occidental way of life", and the coherence or adjustment between individual and cultural lifestyle and behaviour patterns. They assert that cultural variables can work as a moderator for the relationship between psychological factors and hypertension; for example, showing that the expression of negative emotion has a positive or negative correlation with stress depending on the subject's cultural background. This perspective emphasises the need to include context variables in hypertension theoretical models (Anderson, 1989; Butler, Lee & Gross, 2009; Carretero & Oparil, 2000; Krieger & Sidney, 1996).

Finally, regarding regular medical treatment, it includes medication and adoption of healthy lifestyle habits, with the ultimate public health goal of reducing cardiovascular and renal morbidity and mortality, through normalisation of blood pressure levels. More than two-thirds of all patients require more than one antihypertensive drug, and

it's also critical for both preventing and controlling HT the changing of healthy habits such as: weight reduction, a diet high in fruits and vegetables and low in fat, sodium intake reduction, regular aerobic physical activity and moderation of alcohol consumption (NIH, 2003; Kaplan, 2005). Also, recent research has shown that in hypertension, as in other chronic conditions, the progression of the disease can be attenuated, particularly in the early stages, with effective psychosocial treatment strategies, particularly for reducing stress and treating depression, improving treatment cost-effectiveness and patient prognosis (Blumenthal et al, 2002; Bogner & de Vries, 2008; Sperry, 2006). It's also been stated that a selection of specific strategies for different patients is a requisite for optimal treatment (Nezu et al, 2004).

#### **Adherence Studies**

Adherence has been recently defined by the World Health Organisation as the "the extent to which a person's behaviour – taking medication, following a diet, and/or executing lifestyle changes, corresponds with agreed recommendations from a health care provider" (2003, p. 3). Also, it has stated that "increasing the effectiveness of adherence interventions may have a far greater impact on the health of the population than any improvement in specific medical treatments" (2003, p. 21.). In hypertension, low adherence (30–60%) has been identified as the primary cause of unsatisfactory blood pressure control, and therefore the WHO has emphasised that interventions for removing barriers to adherence must become a central component in efforts to improve population health worldwide (2003).

Although non adherence is identified as a problem in most research projects, adherence rates vary greatly between studies, according to: (a) the type of illness, with acute diseases having better adherence than chronic ones, and prevention programs have the lowest; (b) the kind of health behaviour being measured, with medication having better adherence than lifestyle changes; (c) the criteria for classifying a patient as adherent or non adherent, for which there is no universal consensus and varies according to the severity of pathology (in hypertension most studies chose the taking of 80% of prescribed medication as the cut-off point); (d) whether it's intentional or non intentional<sup>2</sup>; (e) the preferred strategy for measuring

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<sup>&</sup>lt;sup>2</sup> Intentional nonadherence is associated to perceived benefits and costs of following treatment, while nonintentional relates to demographic variables (Wroe & Thomas, 2003). The difference between intentional both types has been only recently made, so usually the available data doesn't differentiate the two.

adherence, because there is no "gold standard" (Osterberg & Blaschke, 2005; WHO, 2003).

Regarding measuring methods, they are diverse and can be classified as *direct* and *indirect*. Direct methods evaluate drug concentration in patient's organism and are the most precise, but are difficult to implement and their results are influenced by metabolic and diet differences between individuals, among other factors. Indirect methods are the most widely used and include patient self-report (using clinical interview and questionnaires), review of medical records, residual pill counting, prescription refill rates, therapeutic outcome and electronic measurement devices such as the MEMS method, which records the time and date when a medication container was opened (Ingaramo et al, 2005; WHO, 2003). One of the main problems with this diversity of methods is that adherence data is different according to the measurement methodology, with self-report usually over-representing patient adherence (Faúndez, 2009).

Numerous behavioural medicine and health psychology research projects have aimed to explore and understand patients' non adherence to a treatment that could save their lives (Donohue & Levensky, 2006; WHO, 2003). Most studies use correlational methods and if they include psychological variables, approach them from a cognitive-behavioral perspective and do not explore patients' own experience (e.g. Faúndez, 2009; Jaél, Pintor & Peri, 2004; Sherbourne, Hays, Ordway & DiMatteo, 1992). However, there are other studies that address the key role of patients' beliefs about illness and treatment, most of which are performed with qualitative methods and consider cultural differences as well as a social representations theoretical framework (Creer et al, 2004; Gámez, & Roales-Nieto, 2005; León, Páez & Díaz, 2003; Rabinowitz, 1999; Weiss, 1998). There are still other studies that focus on interactional variables, for example relating doctor's directive behaviour to patient's reactance, understanding non adherence as aiming to regain a sense of agency (Fogarty & Youngs, 2000; Graybar, Antonuccio, Boutilier & Varble, 1989; Rabin, 2004). However, almost no studies consider psychodynamic contributions or include psychological variables outside conscious awareness or patient self-report (Goodman, 1992; Weatherby, 2005).

These studies have found different variables influencing patients' adherence to hypertensive treatment, which have been classified in at least five interacting factors or dimensions (Creer et al, 2004; Donohue & Levensky, 2006; Dressler & Bindon, 2000; Faúndez, 2009; Meichenbaum & Turk, 1991; WHO, 2003):

- 1. *Patient*: self-efficacy and self-esteem, locus of control, problem awareness and information about the illness, social support, coping strategies, beliefs about the disease and treatment, co-morbidity.
- 2. Socio-economic and cultural context: social representations of disease and treatment.
- 3. *Illness*: Evolution, severity, visibility of symptoms.
- 4. *Treatment*: Duration, cost, secondary effects, waiting times, complexity and dosage.
- 5. *Doctor-Patient relationship*: communication, bond, locus control and patient's active participation, patient reactance and doctor directive style.

In order to understand these variables, researchers historically have adopted several theoretical models:

(a) The biomedical model related adherence to disease and treatment characteristics; (b) The behavioural theory emphasised reinforcement over adherent behaviour; (c) Communication perspectives encouraged the development of relational skills for treating patients; (d) Cognitive models like the health belief model, and the theory of planned behaviour, highlighted patients' appraisal of health risks and benefits; (e) Self-regulation perspectives added the mediating role (between health threat and action taken) of illness representations and coping skills. More recent developments include (f) The information-motivation-behavioural skills model, which states that information is necessary but not sufficient for changing behaviour, with motivation and behavioural skills being critical determinants of behaviour change; and (g) The stages of change model (or trans-theoretical model), that follows patient's motivation for change process.

Adherence-improving interventions based on these models use psycho-educative and cognitive-behavioural methodologies, usually integrating multiple strategies such as information, reminders, self-monitoring, reinforcement, counselling, therapy, and

more convenient care (Creer et al, 2004; Haynes et al, 2005). Also, as mentioned before, some intervention guidelines emphasise the relationship between medical personnel and patients, such as the doctor's directive or collaborative style and the importance of enhancing active cooperation instead of a passive stance in the patient (Von Korff et al, 1997). As non adherence is understood as a problem behaviour, product of cognitive biases or irrational beliefs ((L. E. Beutler, Moleiro, & Talebi, 2002; levensky, 2006)), the caregiver's intervention is oriented on fighting or correcting those negative cognitions, reinforcing patient's motivations to adhere and provide information about the dangers associated with the illness.

Despite the magnitude of the adherence problem, literature about interventions to improve it is surprisingly weak, with important innovations being more likely to occur if diverse clinical disciplines work together to tackle the problem, taking into account the resistance that many patients have to taking medicines (Pound, Britten, Morgan & Yardley, 2005).

## Resistance to Change in Psychotherapy

Psychotherapists since the beginning of their discipline have been trying to understand the phenomena of a patient who explicitly wants to get better, is investing time and money for that purpose, but seems to sabotage or at least not contribute to the joint therapeutic work. This phenomenon was first conceptualised as **resistance** by Freud, a force that operates in the opposite direction of change (1912/1958). Although theories differ widely on its causes and methods for dealing with it –and some theorists even propose its demise (de Shazer, 1984)- virtually all theories agree on its "existence" or usefulness (Beutler, Moleiro & Talebi, 2002). In broad terms, resistance can be identified when patients' express desire to change and yet show alternation between approaching and avoiding the tasks necessary for such change to happen (Arkowitz, 2002). This is a conceptualisation that can easily be applied to non adherent medical patients.

Psychotherapy and medical adherence research agree on the key role of patient cooperation in treatment results. A recent review of 50 years of psychotherapy research concluded that patient involvement and cooperation was the most powerful predictor of treatment efficacy (Orlinsky, Ronnestad & Willutzki, 2004). The Stages-

of-Change Model of Behaviour Change has already showed that non adherent patients are often ambivalent towards change (because the benefits of treatment don't outweigh its costs or the immediate rewards of unhealthy behaviour), and that this ambivalence is a very useful predictor of who will terminate treatment prematurely (Brogan, Prochaska & Prochaska, 1999; Calhoun, 2005). Also, from a constructivist perspective, inner conflict about change has been useful to predict who will benefit from a cognitive-behavioural intervention (Carretero, Feixas, Pellungrini & Saúl-Gutiérrez, 2001; Winter, 1988).

How can we understand and deal with resistant behaviour? First, researchers state that not all resistance is equal. Prochaska and Prochaska (1999) point out that people don't change either because they can't, they don't want to, they don't know how or they don't know what to change. Munjack & Oziel (1978) distinguish 5 causes of patients' resistant behavior: (i) because the patient doesn't understand what the therapist wants him to do; (ii) doesn't know what to do or lacks the necessary skills to do it; (iii) is unmotivated; (iv) therapy is producing guilt or anxiety as repressed contents begin to surface; and/or (v) the symptom has secondary gains. Furthermore, theorists have distinguished from intrapersonal and interpersonal determinants of resistance (Arkowitz, 2002: Beutler 2002). Although there are many theoretical conceptualisations of resistance, three different views are presented in this dissertation. These complement the more common understanding of non adherence in health psychology, focused on information and rational beliefs. After discussing these different views, an integrative perspective will be presented, based on a constructivist and dialogical epistemology and anthropology.

#### 2.4.1. Resistance as part of an interaction

Coherent with research findings that put relational variables in the heart of psychotherapeutic change mechanisms -with therapeutic alliance having the strongest evidence of all process-outcome research variables (Horvath, Del Re, Flückiger, & Symonds, 2011)-, this relational approach sees resistance not as something that happens within the client, but rather as a phenomenon that emerges between client and therapist' subjective worlds (Cowan & Presbury, 2000). Therapists and patients can become caught in a complementary pattern that

maintains patients' difficulties, so therapists may fail to recognise their own influence on a particular patient's transference as both participate in the relational field, inadvertently producing what can be later seen as patient's resistance (Arkowitz, 2002; Cowan & Presbury, 2000; Watzlawick, Beavin & Jackson, 1967).

Several studies have addressed this issue using Brehm's concept of reactance (Cowan & Presbury, 2000), which states that individuals are less likely to change if they see other people as pressuring or coercing them into changing, as "the desire to be in control of ourselves and our environment can cause us to resist changes that might otherwise be to our advantage" (Prochaska & Prochaska, 1999, p. 86). Research has shown that therapists' directive style can intensify patients' reactance and thus resistance- to treatment; on the other hand, therapists can use non directive, paradoxical and relationship oriented interventions for patients with reactant states (Beutler et al, 2002). Complementarily, less reactant patients may show higher adherence with more directive communication style from the doctor (Madsen, 2007).

From a different perspective, resistance can be an expression of therapists neglecting patients' motivation, values and point of view (Duncan, Hubble & Miller, 1997). Patients are never unmotivated; they may not share therapists' goals, but they hold strong motivations of their own. So, neglecting patients' agendas or trying to impose therapists' own ideas of what would be good for them, invites resistant behaviour. Also, invalidating patients' point of view asks for resistant responses as a way of 'saving face' or upholding dignity (Duncan et al, 1997).

Motivational Enhancement Therapy (MET, a development of Prochaska's Transtheoretical Model of Change) has designed several strategies for enhancing patient cooperation and preventing therapy dyads from engaging in directive-reactant patterns, among which are: expressing empathy, avoiding argumentation, addressing ambivalence for change in an open and emphatic manner, and emphasising patient's choice and control. These recommendations have had some echo in the treatment of chronic illness, with researchers asserting that patients should be involved in treatment decisions in order to make them active participants who assume responsibility for their self-care (Nunes et al, 2009; Von Korff et al, 2007).

## 2.4.2. Resistance as product of deficit in psychological functions

This perspective focuses on intra-psychic variables to understand resistant behaviour, assuming that sometimes patient show uncooperative behaviour because they can't change or don't know how/what to change (Prochaska & Prochaska, 1999). This emphasis on patient variables relates to research findings that indicate that "the largest proportion of variance in therapy outcome is accounted for by the personal characteristics and qualities of the client" (Clarkin & Levi, 2004, p. 195). Although the relevance of patients' characteristics in the change process is agreed upon by all theoretical models, they differ in their understanding of them.

Psychoanalysis, although originally focused on intra-psychic conflict (Freud & Strachey, 1962), thanks to the works of Balint, Kohut and others, has developed the concept of psychological structure and structural deficit, pointing out that some patients have lacked the necessary parental care or have had repeated trauma and they arrive at adulthood with some self or ego functions underdeveloped or inhibited (Coderch, 2007). For example, it can be hypothesised that a patient with difficulties trusting others, one that has low psychological mindedness, or has poor impulse control, would have difficulties adhering with therapeutic tasks (OPD Taskforce, 2008). This hypothesis relates to the finding that patients with borderline personality disorder (which implies structural deficit) are at high risk for premature dropout (Clarkin & Levi, 2004).

Also originated from psychoanalysis and focused on somatic illness and disease, the psychobiological-dysregulation model conceptualises disease-prone individuals as people who have failed to achieve the usual and proper level of self-regulation, not because of primary psychological conflicts with symbolic significance, but because they have suffered presumed developmental arrests as a result of deficiencies in their earliest object relationships, which are reflected in the quality of their inner self and object representations and by impaired ego functioning (Taylor, 1992). For example, the failure to regulate and modulate distressing emotions at the cognitive level is thought to result in exacerbated physiological responses to stressful situations, which coupled with difficulties recognising their own physical signals of stress could produce conditions for chronic rising of arousal levels and blood pressure (Taylor, 1992). In the chronic illnesses, patients' characteristics such as

coping strategies, self-care functions and fear of dependence (Donohue & Levensky, 2006; Maldavsky, 2009<sup>3</sup>; WHO, 2003) have been related to their adherence.

Although the concept of psychological structure has a psychoanalytic tradition, the emphasis on the availability and development of patients' resources and skills has extended to very different theoretical orientations, such as Cognitive-Behavioural (Linehan, 1993) and solution-oriented approaches (de Shazer, 1984). The main difference is that these perspectives don't agree with psychodynamic emphasis on deficit rather than client's resources and potential. Also, some researchers in this tradition have warned about the danger for self-fulfilling prophecies when assessing patients as resistant or difficult, because they operate under different rules and values, or don't seem to respond as expected by the therapist's theory of choice (Duncan et al, 1997; Engle & Holiman, 2002; Kottler, 1992).

A recent perspective on resistance is that offered by the Operationalised Psychodynamic Diagnostic system (OPD). Designed for use on clinical and research settings, it defines *psychological structure* as the availability of psychological functions regarding regulation of self and relationships with internal and external objects. It's classified in high, medium, low and disintegrated levels, which are not rigid or unalterable, but are so slow changing that seem stable in time. Each individual's psychological structure includes the following dimensions: (i) self and object perception; (ii) self and object regulation; (iii) emotional and communicational skills; and (iv) attachment or bonding capabilities with internal and external objects (OPD Taskforce, 2008).

#### 2.4.3. Resistance as an adaptive response to conflict

Conflict can be defined in general terms as the presence of different positions within a person, implying a contradiction of desires, needs, values and /or representations (OPD Taskforce, 2008). This is coherent with the conceptualisation of resistance as ambivalence (Arkowitz, 2002), implying that the problem / symptom / status quo has a positive value or is associated with an important motivation for the "resistant" client, and that positive value is what is opposing change and producing resistant behaviour. For example, in psychosomatic disorders, the difficulty in affect regulation

<sup>&</sup>lt;sup>3</sup> D. Maldavsky, personal communication, 27 June 2009.

(a structural deficit) contributes to the patient's use of maladaptative coping strategies for self-soothing and reducing emotional tension, such as overeating, which in the case of an hypertensive patient would evidently difficult his adherence to diet recommendations, because doing so would increase his anxiety and distress.

This view has been shared by multiple theoretical perspectives: family therapists coined the term function of the symptom (Selvini-Palazzoli, Boscolo, Cecchin & Prata, 1989); psychoanalysts use the terms conflict, primary and secondary gain (Coderch, 2007); Gestalt and humanistic therapists prefer the metaphor of different parts within the personality (Ecker & Hulley, 1996; Engle & Holiman, 2002); the Transtheoretical Model of Change uses the terms ambivalence and motivation for change (Prochaska & DiClemente, 1983); Neuro-Linguistic Programming has coined the concept of symptom's positive intention (Bandler & Grinder, 1980); Personal Constructs Psychology uses the concept of implicative dilemma (Winter, 1992); other therapists from a constructivist perspective have used the concept of positions (Ecker & Hulley, 1996; Frankel & Levitt, 2006) while others view resistance as a selfprotection strategy, a natural manifestation of self-preservation in the face of threatening change (Frankel & Levitt, 2006; Mahoney, 1991). They differ on the analysis level (family, self, specific problem) and relevance given to unconscious or conscious aims, but all share an understanding of resistance as result of motivational conflict.

Several research projects have pointed out the clinical relevance of addressing patients' conflicts or ambivalence to change in order to improve cooperation and outcome. Personal Constructs Psychology has shown that in many cases of chronic or long term problems, they are associated with positive aspects that define patient's identity. For example, people with social phobia may associate their desired extravert features with undesired traits like vanity, insensibility, arrogance, etc., presenting resistance to treatment and not benefiting from a social skills training program unless those implicative dilemmas are worked through (Fransella & Crisp, 1979; Winter, 1992). Also, the Stages of Change model has been used to predict premature termination or dropout in psychotherapy and various health related problems (Prochaska & Prochaska, 1999). According to this theory, premature terminators are patients that don't have any motivation for change because don't see a problem (pre-

contemplation stage), or do perceive one but are ambivalent towards change (contemplation), with resistant behaviour often occurring when therapists treat their patients as if they are ready for change (preparation or change stages), giving advice, homework or information and neglecting to address motivation issues (Miller & Rollnick, 2002; Prochaska & Prochaska, 1999).

## Constructivism and Dialogism as meta-perspectives for understanding resistance

The following paragraphs present the two fundamental paradigms that allow this dissertation to integrate the previous three diverse theoretical perspectives: Constructivism & Dialogism.

# 2.5.1. Constructivism: Behaviour as coherent with current construction of reality

All of these theoretical perspectives are integrated within a postmodern and constructivist framework (Frankel & Levitt, 2006) that regards resistance as an ally rather than an enemy, contrary to most cognitive and behavioural theorists who understand resistance as simple non-compliance, an obstruction to goal achievement that needs to be overcome (Beutler et al, 2002). The constructivist paradigm assumes that there is no objectively 'correct' version of reality, and that "each person actively forms or assembles the experiential reality, the experiential world of meaning that he or she inhabits and takes as independent, real, and self-evident" (Ecker & Hulley, 1996, p. 5). In this view, problems are generated by the individual's cognitions and emotions comprising his present construction of reality (Ecker & Hulley, op. cit.).

Another key assumption in this perspective is the inner coherence of the self, believing that every activity of the mind, conscious and unconscious, is coherent with its present constructions of meaning (Toomey & Ecker, 2007). Therefore, "people behave essentially according to what they construct as the most adaptive alternative, from their current perceptions (schemas, constructions) of themselves and their situation" (Greenberg, Rice & Elliot, 1996, p. 107), in a purposeful attempt to satisfy desires and interests established by those constructions of meaning (Ecker & Hulley, 1996). These schemas or constructions are dynamic and can be explicit or implicit. Also, different contexts can elicit different schemas (Arkowitz, 2002; Ecker & Hulley,

1996), with various degrees of conscious awareness, and with the possibility of more than one operating simultaneously and with autonomy.

So, when change is desired consciously but not happening (assuming the person has the abilities and information for change to occur), there may be more than one schematic structure operating simultaneously: one part desiring change and one opposing it (Arkowitz, 2002). This part that opposes change has been called *prosymptom position*, an unconscious construction of reality in which the symptom (problem, unhealthy behaviour, etc.) seems necessary to have (Ecker & Hulley, 1996). This position would be the construction of reality that makes having the symptom/problem behaviour valuable, as "only viewing the symptom in the symptom-positive context(s) does it become clear how the symptom is more important to have than not to have" (Ecker & Hulley, 1996, p. 96).

The pro-symptom position is similar to Motivational Interview and Stages of Change Model's concept of *anti-change motivation* (Miller & Rollnick, 2002), as these theories view cooperation and resistant behaviour as resulting from the balance of pro-change and anti-change aims. The difference is that the constructivist view of *position* emphasises unconscious constructs and schemas, and thus, by definition, is very difficult to explore via direct self-report measures or interviews directed only towards conscious and rational-level contents. Ecker & Hulley affirm that patients can become aware of their unconscious positions, but that requires appropriate interview and exploration techniques (1996).

A clinical example can illustrate the concept of pro-symptom position:

A very alienated and unhappy couple described their 'communication problem': the wife complained that her husband viewed everything she said to him as criticism, and that he would therefore counterattack and behave as though they were adversaries. He agreed but saw this as her fault; he felt she continually attacked him emotionally and verbally. The therapist then explained that he needed to do an experiment [...] and coached them though a few minutes of amicable interacting, free of the construal of 'attack'. When the therapist asked them how they were feeling, the wife said "relieved", and the husband said "defenseless". He

was quiet for a few seconds and then added, 'all I can tell you is, now I feel unjustified in sticking up for myself'. A few more steps of inquiry drew out the unconscious emotional reality in which the man usually lived, a reality in which expressing his needs and desires is 'bad and selfish', except when he is under attack. [...] His disentitlement to self-affirmation now became the focus of therapy (Ecker & Hulley, 1996, pp. 8–9).

As shown in the clinical vignette above, without addressing the position that made the problem necessary to have, any attempt by the therapist to improve the couple's communication skills would have resulted in resistance from the husband. So, if the problem behaviour or symptom has an important purpose, this aim must be fulfilled or addressed in a different way, or else the patient will show resistance. Applying this to chronic illness, it can be concluded that factors influencing patient non adherence must be understood by both the client and therapist, so they can work together to make new choices regarding treatment (Engle & Holiman, 2006).

## 2.5.1. Dialogism: The self as multi-voiced and the centrality of the recipient in human communication

As implicit in the notion of *positions*, this theoretical model views the self as devoid of a central core, but instead being composed of different parts, modules, subpersonalities or voices (Dimaggio & Stiles, 2007; Hermans, Kempen, & Van Loon, 1992; Honos-Webb & Stiles, 1998; Kurzban, 2011; Lester, 2007; Rowan, 2010). In these conceptualisations, dissociation and incongruence between different voices is not seen as a phenomena only present in pathology, but instead as a normal feature of human experience and brain evolution (Kurzban, 2011; Rowan, 2010). Also, different positions in the dialogical self can each have their own wishes, feelings, memories and resources (Hermans, 1996), even if they are rejected or non consciously accessible by more dominant parts in the self's community of voices (Gonçalves et al., 2011). Finally, these voices are activated in a specific time and experiential context, so in one moment a *pro adherence* voice can be salient and dominating, and in another an *anti adherence* voice can have control (Hermans, 2003; Valsiner, 2002).

Regarding treatment and intervention goals, from this perspective it's not enough to empower the explicit pro change voice (the only one usually known to researchers, practitioners, and even consciously to the patient himself). For lasting change to occur, these implicit *anti-adherence* voices should not be rejected or fought, but acknowledged, integrated or assimilated (Hermans et al., 1992; Honos-Webb & Stiles, 1998).

In general, it is said that exclusive dominance of one part of the self over all others is problematic, and that an aim of therapy should be to help patients be aware and acknowledge parts of the self previously in the shadows (Dimaggio & Stiles, 2007). For example, Stiles' Assimilation model states that when a voice is not accepted into the dominant community of voices in the self, it becomes problematic and arises in symptomatic or conflicting ways (Honos-Webb & Stiles, 1998). In this view, a healthy self is flexible, having the potential to move from one self-position to another in order to respond adequately to changing contextual demands (van Geelen, 2010).

Besides its emphasis on multiple voices, dialogism follows Bakhtin's revolutionary views on utterances and communication (Leiman, 2004). Traditional or common sense view regards the speaker and content as the main features of utterances, but Bakhtin changed this, placing the focus on the addressee or recipient (Leiman, 2004; Salgado & Cunha, 2011). This means that the speaker, and human communication in general, doesn't exist in a vacuum, but instead in a shared intersubjective space, and the others sharing that space -the recipients- affect every aspect of the utterance, even its content. So, every thought or behaviour is shaped by the presence of an factual or imagined, external or internalised other. The self is not isolated or monological, but constructed in dialogue with others and between different internal parts (van Geelen, 2010).

Dialogism and constructivism help integrate the different theories and findings presented above. Interactional systemic views can be seen as an external perspective on the dialogical exchange, while psychoanalysis' focus on transference and counter-transference can be seen as providing an internal perspective on the same exchange, but more focused on internalised others. Regarding conflict and deficit perspectives, from a constructivist perspective the individual responds in the most adaptive way, according to available possibilities in the present construction of

reality (or *position*). The conflict perspective states that inner quarrel arises when there are different and opposed constructions of reality, each with its own *adaptive* response. Finally, the deficit perspective, from a constructivist viewpoint, suggests that when someone has higher structural resources, he'll experience a construction of the world with a wider array of possibilities, and thus a reduced chance of conflict.

Therapeutically, this perspective declares that ignoring resistance makes psychotherapeutic work more difficult and less efficient (Miller & Rollnick, 2002), because "there are reasons for resistance that need to be respected and understood [...] when people erect obstacles to personal change, they are doing so for reasons that are valid and important, whether or not these reasons are available to conscious awareness" (Arkowitz, 2002, p. 220). Therefore, fighting the 'resistant' or 'anti adherence' voice would generate more resistance, while acknowledging and accepting it could open possibilities for cooperation and change.

## **General Design of the Study**

The design of this study is non-experimental, cross-sectional, exploratory, descriptive and comparative. Qualitative analysis will be used in order to access patients' experience and subjective processes from their own perspective (Glaser & Strauss, 1967; Hill et al., 2005), using Grounded Theory procedures for constructing theoretical models inductively from the data recollected about the studied phenomena (Krause, 1995). Qualitative data will be complemented with quantitative descriptive data, categorised according to Consensual Qualitative Research (CQR) guidelines (Hill et al., 2005), and used to compare characteristics of subgroups in the sample (for example, comparing patients with high and low adherence).

The general design is emergent, based on Grounded Theory principles in order to develop theoretical hypothesis from the data. This design includes two main stages or phases: The first one is exploratory, to make a first approximation to the data, develop relational hypotheses and choose the foci and methods for further analysis in the second stage. The second stage is descriptive and relational and will have the results of the first stage as a starting point. It's aim will be to gain deeper understanding of the phenomenon, comparing different subgroups within the global sample.

Each of the two empirical papers included in the dissertation has its own specific methodology. However, below the general methodological process along both stages is presented:

#### Stage 1

After designing the interview and observation guides, three pilot interviews were made to refine the methodology (these interviews were subsequently incorporated in the study, as were eligible for inclusion). Subsequently, two public health institutions were contacted to solicit collaboration in the study, obtaining authorisation. Then, the collaboration methodology with the other researchers was defined, agreeing to a weekly meeting between two team members, plus a biweekly meeting of the full three people team.

Once the project was accepted in the two health institutions, the next step was to contact some of the institution's medical staff, specifically those who work with hypertension patients. These professionals were asked for a personal interview, to consult their patients if they could be interviewed, and if they could be recorded in an individual or group health control session. In this way most of the sample at this stage was gathered, except for a couple of participants who met the intentional sampling criteria and were known to members of the research team. Once the permission of the participants was obtained and the informed consents were signed, data collection began. Then, weekly analysis meetings with the research team were conducted, in order to refine the interview guide and ensure that the sample was representative of different adherence levels.

Data gathered in stage 1 was comprised of:

- 15 patient interviews (see appendix 1 for the interview guide).
- Non participant observation of 14 individual and 3 group health control sessions (see appendix 2 for the observation guide).
- 6 caregiver interviews, including 2 nutritionists, 2 nurses and 2 physicians (see appendix 3 for the interview guide).

## Preparation of Stage 2

This phase started with a series of relational hypotheses, detailed in Appendix no 7. Taking them as a starting point, it was decided to focus stage two only on patient interviews, and the interview guide was redesigned, to allow exploration of the different topics involved in the hypotheses. Furthermore, patients' different adherence levels were operationalised, and a specific part of the interview to explore adherence levels in detail was developed. Also, the need for more patients from the private health sector was noticed, along with more that had dropped out of the treatment. Another key decision was to eliminate the originally planned stage three of the study. This was supposed to be a quantitative, correlational phase, and was replaced with the decision to use CQR to compare between subsamples, allowing to explore relations between different factors. This decision was made towards achieving greater depth in the qualitative analysis.

Finally, there was the need to find a way to explore patients' constructs, schemas and conflicts, regarding adhering and not adhering to the treatment. In order to do this, in stage 2 specific interview techniques to explore these often elusive meanings were defined (see Appendix nº 4b). Also, a theoretical research began, to find comprehensive models that allowed understanding the simultaneous presence of two or more positions or attitudes (e.g. adhering and not adhering). This research led to the adoption of dialogical self theories as a basic part of the theoretical framework of the study. Also, this new phase of theoretical research included some background on patient-caregiver power relations, and the treatment decision making process.

## Stage 2

Two new psychologist-researchers were included for data recollection, and later four more (one of them a psychoanalysis specialist, two of them under-graduates doing their clinical practice) for data analysis triangulation with the main researcher. The new sample was contacted using the theoretical sampling criteria, from the original two public health institutions and also from the researcher's personal networks. Every interview was recorded in audio and video, and later transcribed. Each interview was analysed by the main researcher and one of the other members of the team. Parts of the research team met weekly to discuss the findings, change the interview guide, and re-define the criteria for recruiting new participants in the sample.

Once the data recollection was finished, the main researcher started a training period, designing the methodology for analysing the data. This implied more research on dialogical self theories and also training on the Operationalised Psychodynamic Diagnostic system (OPD) (OPD Taskforce, 2008). After this, a 5 member team was assembled for the analysis, and again every interview was analysed, using a data sheet with complete information on every topic (each column was one category and core idea) for every patient (in each row). So, for every patient, presence or absence of each core idea was coded, from every domain or category.

At the end of all this process, the original category tree was refined and actualised, the original hypothetical models were revised, and new models were developed from emergent data. Then, the main researcher defined the topics for writing the three papers included in this dissertation.

## Presentation of the three attached papers

Included separately are the three papers that represent different aspects of the overall dissertation. The first one shows the theoretical perspective used in the study. The second showcases findings about the patient-caregiver interaction, differentiating two different "prototypes" of patients, according to their personality and relational traits. The third and final paper focuses on patients' implicit positions or voices regarding non adherence, trying to understand the subjective meaning of their resistant behaviour, and also the different ways they deal with their ambivalence. The specific objective of exploring and describing patients' experience of the treatment process over time is not represented in these papers, but is included in the subsequent general conclusion.

Paper 1: Why some patients don't adhere to medical treatment? Contributions from psychotherapy research to the study of chronic illnesses' treatment adherence

Paper 2: Towards a relational understanding of non adherence to medical treatment: Interactional patterns in the doctor-patient relationship

Paper 3: Conflict and ambivalence in chronic illness patients with high and low adherence to medical treatment. A dialogical self analysis

1. Why some patients don't adhere to medical treatment? Contributions from psychotherapy research to the study of chronic illnesses' treatment adherence

Author: Pablo Herrera S.

**Abstract** 

Patients' low adherence to medical treatment in chronic illnesses is one of the

biggest public health problems. Numerous Health Psychology and Behavioural

Medicine studies have helped understand different factors related to patient

adherence. However, these theoretical models have not been able to fully explain the

ambivalence of those patients who ask for medical assistance, but nevertheless fail

to follow the treatment as agreed. For this reason, these models fail to suitably

predict patients' future behaviour, only predicting their conscious intention to adhere.

In this situation, this article proposes a complementary theoretical framework for

understanding patient adherence. From this perspective, adherence is understood as

an emergent phenomena in the interaction between patient and treatment (not as an

intrinsic quality of the patient). Also, patients' ambivalent behaviour is understood as

a manifestation of different "voices" o inner positions within the self, each one with

their own motivations, experiences and reasons for adhering or not adhering.

From this theoretical framework, we suggest patients' behaviour to be analysed

together with treatment characteristics and caregivers' interactional patterns.

Likewise, as a strategy to approach non adherence, we propose empathic

exploration of patients' inner voices that oppose adherence, instead of the usual

attitude of arguing towards reinforcing the more conscious, pro adherence, patient

position.

Key Words: Adherence, Chronic Illness, Resistance, Dialogical Self

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#### 1.1. Introduction

We currently live in a transition period from a predominance of acute and infectious diseases, towards more chronic conditions (1, 2), whose treatment requires lifestyle changes (diet, exercise, healthy behaviour). Although efficacious treatment protocols have been developed, results are unsatisfactory (3, 4). For example, less than 30% of all Hypertensive patients manage to normalise their blood pressure level (2, 5). The World Health Organisation has identified low patient adherence as the main cause of chronic conditions poor control (2). In Hypertension and type II Diabetes, adherence fluctuates between 30 and 60%, half of all patients stop taking medication within the first year of the treatment (6, 7), and lifestyle changes have between 75 and 80% failure rates (8). This is not usually perceived by health care professionals, who often overestimate their patients' adherence (9).

Different models have been used to explain adherence, identifying factors related to the patient, treatment, illness and patient-caregiver relationship (2, 3, 10, 11, 12, 13). However, interventions based on these models are resource intensive and have presented moderate and difficult to sustain results (3, 8, 14). Theoretically, one important criticism is that even though they have tried to find the psychological profile of non adherent the patient, findings have been inconsistent and contradictory (9). For example, some studies state that patients with internal locus of control adhere better, while other claim the opposite (9).

Another relevant criticism is that traditional models manage to explain the conscious intention to adhere, but don't predict the future behaviour (9, 11). This means that they are not sufficient to explain the large amount of patients that acknowledge good reasons for adhering, yet don't do it. These expressions of ambivalence (i.e. discrepancy between intention and behaviour) have shown to have huge clinical relevance. For example, studies have shown that only 20% of all people who have unhealthy behaviours are motivated and prepared to change, while the remaining 80% are ambivalent towards change, or don't see the need for it (15).

#### 1.2. Towards a new comprehensive model of non adherence

The difficulty understanding non adherent patients' behaviour is not exclusive to medicine or health psychology. In the psychotherapy field, researchers since Freud

(16) have been asking why many "resistant" patients seem to sabotage or not cooperate with therapy and professionals who want to help them (17, 18). However, behavioural science and psychotherapy findings and theories have not been considered enough for understanding patient non adherence, and there is an enormous potential of untapped knowledge (8, 9, 19, 20).

This theoretical paper aims to complement the traditional understanding of non adherence in health psychology, using theoretical and empirical developments in the psychotherapy field. Particularly, it proposes two changes in the way patient adherence has been traditionally conceptualised:

- A. Instead of an individual phenomenon located in the patient, a relational phenomenon that cannot be analysed independently of the treatment context and the interaction with the caregivers (9, 17, 22, 23).
- B. Instead of considering adherence the only positive option, understanding non adherence as an adaptive and valuable response, coherent with patient's existing constructions of reality (implicit or explicit) and his available psychological resources and possibilities (21, 24, 25, 26, 27).

#### 1.2.1. Non adherence as a relational phenomenon

This perspective conceptualises non adherence (or resistance) not as something localised in the patient, but as an emergent phenomenon between patient and caregiver (22). In the medical field, several studies have already emphasised the importance of generating a collaborative and empathic context with patients (28), and also establishing a good interpersonal relationship (29), in order to improve patient's adherence. However, understanding resistance as a relational phenomenon is different. It implies that when studying adherence it's not enough to observe the patient, being necessary to consider at the same time his interactional context. In this regard, it wouldn't be right to say "resistant patient", being more correct to talk about a "patient resistant to a specific intervention". This means that a patient can appear resistant to a particular program or caregiver intervention, but show himself to be "cooperative" towards another. Therefore, resistance is not an intrinsic quality of the patient, but a contingent response to a specific intervention or interactional style.

In psychotherapy research, this perspective has been developed by Larry Beutler, showing that patients who wish to preserve their autonomy respond better to non directive interventions, while those who are more open to therapists' influence respond better to directive interventions (17, 30). The same idea has been researched in medical contexts (9, 31, 32, 33). For example, it was found that for dialysis patients, those who had a more independent and vigilant style fared better with a treatment modality that emphasised self-control (peritoneal dialysis) and worse in another that put the patient in a passive role (dialysis in a health institution). The opposite results were observed in less independent and vigilant patients (9).

Bellow we present two clinical vignettes to illustrate this with hypertensive patients:

## Olga, 78 years old

Olga has always been an independent woman that has been in charge of her daughter and grandchildren. She worked as a teacher and then supervising public schools, until retiring at 65 years old. Then, she's dedicated herself to running the house and cooking for her family. She's always had good health and is very attentive of her diet and exercise. She was diagnosed with hypertension one year ago, and in her own words:

"At the beginning I was very rebellious to this, it shocked me to be slaved to medication... with the first doctor we didn't get along, because he told me that I needed to do this and that and didn't listen to me, and I don't think that's right, because the doctor knows you only partially, and you know yourself pretty well. So I left that doctor."

#### Sara, 52 years old

Sara is a very sociable woman that, after her children stopped depending on her financially, happily assumed domestic work and let her husband be the sole economic provider. Regarding hypertension, she reports two very different experiences with caregivers:

The first made me think he didn't care about me. I told him that I was forgetting the medication, that the diet was difficult, but it was like he didn't care. The only thing he did was repeat to me the risks of hypertension, which I already knew."

Now it's completely different, the doctor is very happy with me. She's different than the last one, when I told her the problems I had, she scolded me very hard! And that made me wake up and realise that I had to take the illness seriously."

Commentary: Olga and Sara's vignettes illustrate how the caregiver's "directive" style has very different effects according to the patients' personality characteristics. In Olga's case, she felt her freedom had been restricted (and for her, as an independent woman, that was very important), and thus abandoning treatment with the first doctor meant restoring her sense of autonomy. In Sara's case, she experienced the non directive behaviour of her first doctor as disinterest, in contrast to the more directive attitude of the second caregiver, which she experienced as a sign of caring.

Furthermore, one can observe how for Olga the subjective position in which the doctor is placed (the doctor knows you only partially, and you know yourself pretty well) is very different from Sara's (the doctor is very happy with me).

# 1.2.2. Non adherence as an adaptive response

Traditional models to comprehend non adherent behaviour regard it as a problem behaviour that needs overcoming, a product of irrational beliefs or cognitive biases (17, 19). Under this assumption, the clinician's behaviour must be directed towards fighting these negative beliefs and reinforcing the patient's motivations for adhering, for example clarifying fears about medication side-effects or alerting about the dangers associated with the illness. However, as has been already mentioned, rational and conscious arguments are not sufficient to explain the patients' adherence behaviour (9, 11). Below an alternative model is presented, one that doesn't regard non adherent behaviour as a manifestation of irrational beliefs, but as an adaptive response, the best option for the patient according to the available resources and the implicit schemas active in that moment.

According to this paradigm, all human behaviour can be understood, including symptoms and resistance, as coherent with the personal constructs and schemas (often implicit or not easily conscious) active in a particular context (24, 25). These personal constructs and schemas have been denominated *voices* by Dialogical Self theories (27, 34, 35). These theories regard the self (not only in dissociative or borderline cases) as composed by multiple parts or inner *voices*, all relatively independent and with their own motivations, resources, experiences and relational patterns (27, 34, 35). So, if a patient shows ambivalence by not adhering but wanting to, it's possible that he has an explicit voice that wishes to adhere (the one known to

researchers and caregivers), and an often implicit one that doesn't want to adhere, but also needs to be heard. As Arkowitz states, there are reasons for resistance that need to be respected and understood [...] when people erect obstacles to personal change, they are doing so for reasons that are valid and important, whether or not these reasons are available to conscious awareness (21, p. 220). So, fighting the anti adherence voice would generate more resistance, while accepting it could open possibilities for cooperation (24, 26).

There is little information about studies that apply this understanding in the medical health field. Motivational interviewing research explores patients' ambivalence towards adhering, but focuses mainly on the relative weight of *pro* and *anti* treatment motivations, not its content (23, 26). Recently, a study explored the subjective meanings and internal voices of teenagers with chronic fatigue syndrome from a Dialogical Self perspective (34). In psychotherapy there is a line of research inspired by Personal Constructs Theory about resistant patients trying to protect aspects of their self-concept, for example social phobia patients who implicitly associate improving their social skills with becoming aggressive and arrogant (37, 38). Furthermore, different authors (24, 39, 40) suggest that when a patient shows some deficit in his psychological resources, it's possible that the resistant or harmful behaviour is valuable to compensate that deficit, or even the only available option for the person in that moment.

Bellow we present a clinical vignette to illustrate this with a Diabetes II patient:

#### Rodrigo, 53 years old

Rodrigo, C.E.O. Of a medium-sized company, has been able to adequately deal with his diabetes. However, he can't lose weight, in spite of trying numerous diets and showing strong willpower in other areas of his life. When asked about the illness, he's informed about the benefits and costs of adhering to the treatment plan, showing motivation and declaring that he just doesn't understand why he can't lose the extra weight. When exploring this topic, he says:

"The stress is just too much, every day. Previously I smoked, but it's years now since I quit. Now, while I negotiate with clients I eat some candy, a sandwich, almonds...". When asked what would happen if, in those stressful moments, he restrained from

eating those high calorie foods, he says: "I try to eat healthy but if I don't allow myself that I'd go crazy, or I'd need to start smoking again".

Commentary: In Rodrigo's case, the non adherent behaviour (overeating) has an important emotional regulation function. In the situation where the problem behaviour appears (high occupational stress moments), even though overeating is harmful to the part of him that wants to adhere, it's the best available option at the moment, given that the only other perceived option would be to start smoking again. Furthermore, it's interesting that this adaptive function only becomes clear after detailed exploration, and not spontaneously at the beginning of the interview. So, it's possible to think that the *pro adherence* voice was consciously available throughout the interview, while the *anti adherence* voice was hidden until the situation was explored in more detail and with specific interview techniques.

#### 1.3. Discussion

Below we present a summary table comparing what we have called the *traditional* paradigm and the one suggested in this paper:

Table 1: Comparison between traditional and suggested views of patient non adherence

	Traditional view	Suggested view	
Understanding of non	Obstacle to treatment	Ambivalence, conflict	
adherence	goals	between opposed voices	
		in the self	
Theoretical framework	Rationalism, cognitive-	Dialogical self &	
	behavioural theories	systemic theories,	
		constructivism	
Focus	Non adherent patient	Patient-caregiver &	
		patient-treatment	
		interaction	
Clinical management of	Motivate or convincing	Acknowledging	
non adherence	patient of the importance	ambivalence and	
	of adhering; discussing	accommodating anti	
	obstacles or irrational	adherence voices,	
	beliefs that motivate non	adjusting treatment if	
	adherence	needed	
Research - data	Patient self-report	Indirect & in-depth	
recollection methods		methods for exploring	
		subjectivity and opposed	
		voices in the self	
Research - data	Separate main effects of	Interaction effects	
analysis methods	patient and treatment	between patient and	
	variables	treatment variables	

What does this alternative paradigm on resistance and non adherence imply?

On a clinical level, the relational model of adherence means that it's necessary to know the patient and adjust the interventions to his psychological traits. For example, behaving in a more directive manner with less reactant and more open to influence patients, and on the other hand behaving more horizontally and fostering participation with patients that need to protect their autonomy (9, 17). This means changing the caregiver's behaviour according to the patient. On a methodological level, the relational model implies collecting data about patient and intervention characteristics, and doing quantitative analyses not only considering direct effects of each variable separately, but also analysing possible interaction effects (9).

Regarding the adaptive model of resistant behaviour, due to the lack of research in the medical health field, only exploratory ideas based on psychotherapy research can be offered (24, 25, 26). The main takeaway is that it's equally important to reinforce the pro adherence voice (for example showing the risks of non adherence), than to communicate to the anti adherence voice, understanding its motivations and experiences. First it's necessary to bring it into awareness, for which it's useful to explore in detail the contexts in which non adherent behaviour appears (in Rodrigo's case, when he has stressful conversations with clients), and then explore what would hypothetically happen if, in that same context, the person behaved in an adherent manner (in the same case example, Rodrigo's anxiety would rise and he'd start smoking again). After bringing it into awareness, the second task is exploring its meaning: Does resistant behaviour serve any purpose or important function for the patient, in the context in which it appears?; and does adhering to treatment require the patient to do something that is beyond his capabilities in that moment? Answering these questions would lead to the third and final step: Adjusting the treatment to accommodate the needs and motivations of the anti adherence voice. In Rodrigo's case, this would mean helping him develop alternative and healthier mechanisms to cope with occupational stress.

Methodologically, this means developing methods and techniques to explore the different voices that determine patients' adherence, which implies paying attention to implicit affective meanings (34). From this perspective, using a self report questionnaire to assess conscious rational beliefs, even though it's the most common and cost-effective method, would not be the most appropriate, as it only allows access to the most consciously available voice, the one active when completing the questionnaire. Thus, this method leaves in the dark the other voices of the self, the ones responsible for the problem or resistant behaviour (34).

In the end, this paper proposes that non adherence will remain a mysterious phenomenon as long as its context remains disregarded, both relational as well as subjective. It's necessary to consider what does adhering mean for the patient (for the "whole patient", including his different voices), and also what does it mean relationally to adhere, not thinking only about a "resistant / non adherent" patient, because we will never completely isolate the patient's behaviour from the treatment

and the caregivers. Nevertheless, for this paradigm change to occur, two traditionally detached worlds need to converge (9): Health professionals need to open and consider adherence as a psychosocial problem, taking into account developments in the behavioural sciences; and the same can be said for psychotherapists and social scientists, who usually regard adherence as a medical or physical issue. We hope, with this paper, to have contributed a grain of salt towards bringing these worlds closer together.

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# 2. Towards a relational understanding of non adherence to medical treatment: Interactional patterns in the doctor-patient relationship

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#### Abstract

Patients' low adherence to medical treatment in chronic illnesses is one of the biggest public health concerns. Numerous studies have helped understand different factors associated with it. However, most adherence research regards adherence as an individual phenomenon, disregarding alternative ideas about patients' resistance. This study uses qualitative methods to explore patient-caregiver interactional patterns, relating them to patients' adherence. 51 hypertensive patients' interviews were conducted. Analyses were made from a theoretical perspective that regards non adherence as a relational phenomenon, focusing on identifying interactional vicious circles that involve both participants. Results show two very different patient prototypes: those who keep control and those that give up control of the treatment. Also, each prototype of patient engages the caregiver in different interactional patterns, some associated with high and some with low adherence. Finally, this study argues that in order to intervene effectively with patients, it's possible and necessary to assess key aspects of their relational style, including how they relate to their internalised authority figures.

Key Words: patient-caregiver interaction, adherence, resistance, chronic illness

#### 2.1. Introduction

The World Health Organisation (WHO) has pointed poor treatment adherence as the main cause of poor efficacy in the treatment of Hypertension (HT) and other chronic conditions (World Health Organization, 2003). Even though effective treatment plans are available, patients' adherence to them is between 30 and 60% for medication intake and lower for changes in diet and exercise (L. R. Martin, Williams, Haskard, & Dimatteo, 2005). In understanding this phenomenon, several patient, illness, treatment and patient-caregiver relationship factors have been identified (Christensen, 2004; Donohue & Levensky, 2006; Meichenbaum & Turk, 1987). However, prevailing models haven't been able to predict patients' adherence behaviour, only estimating their intention to adhere (Christensen, 2004). Also, intervention programs to improve patients' adherence are very complex, resource-intensive and have shown moderate results (Haynes, Yao, & Degani, 2005).

One of the main variables that have been studied is the interaction between patients and caregivers. Research in health and clinical psychology (Facchini, 2004; Santibáñez, Román, & Vinet, 2009; Schmid Mast, Hall, & Roter, 2008; Zhang et al., 2011) has shown the importance of a collaborative and empathic communicational style from the health professional, as well as a relationship where treatment goals and tasks are agreed upon. Nonetheless, several authors from health (Christensen, 2000) and clinical psychology (Beutler, Moleiro, & Talebi, 2002; Cowan & Presbury, 2000) backgrounds have challenged the traditional paradigm for understanding non adherent and resistant behaviour. They argue that it's a mistake to think of it as an individual phenomenon, being more useful to regard it as a relational emergent quality. So, resistance and non adherence would be a product of the patient-caregiver interaction in a particular context, and shouldn't be analysed independently of that relational context. This implies that a patient can appear resistant before a particular type of intervention or interaction with the caregiver, and show himself cooperative towards another kind of intervention.

Although there are already studies that apply this perspective to the field of chronic disease (Christensen, 2004), they use exclusively quantitative methodologies, don't describe in depth the interactions between patients and healthcare professionals, and disregard important theoretical developments from psychotherapy and

behavioural sciences (Willey, 1999). In this scenario, the present study aims to explore and describe the interaction between patients and their caregivers, relating these interactional patterns with patients' adherence. In order to do this, in-depth interviews were conducted with 51 hypertensive patients, which were analysed using qualitative methods.

# 2.1.1. Non adherence as a relational phenomenon

Several authors, based on General Systems Theory and Cybernetic models, have understood human behaviour as a relational phenomenon, not reducible to the isolated actions of one of the participants in the system (Watzlawick, Beavin, & Jackson, 1967; Wittezaele & García, 1994). For example, in the case of medical non adherence, from an individualistic, monological viewpoint one could say that the patient has resistant traits or the caregiver lacks empathy. Instead, from a relational perspective both are trapped in a vicious circle in which the caregiver insists and enforces his authority because of the patient's careless and oppositional behaviour, and the patient shows resistance to protect his autonomy from the caregiver's authoritative manner.

Psychoanalysis explains these vicious circles as signs of internalised object relations. For example, the Operationalised Psychodynamic Diagnostic system (OPD) assesses patients' internalised and dysfunctional relational patterns, and how these are triggered at certain contextual cues (OPD Taskforce, 2008). From this perspective, relational problems are composed of the patient's implicit relational offer (how he conducts himself before the therapist, and what role he invites the therapist to play) and the therapist's counter-transferential response (if the therapist embodies the role he is invited to play). This model states that the more rigid these relational patterns are, the harder it is for each actor to "step out" of the counter-transferential role and establish a different kind of interaction.

Other authors have emphasised that some relations are symmetrical, based on similarity, while others are complementary, based on difference (Watzlawick et al., 1967). Following these concepts, Berne (1964) indicates that in human interaction, the person can position himself towards others in three different ways: Father (critical and authoritarian, or nutritious and caring), Adult (when he makes decisions, gives or

asks for information, etc.) and Child (either adapted and well-behaved, or rebellious and naughty). The individual's position interacts with the other's position, either complementing each other or in tension. For example, if one person positions himself as a Father and the other as a child, their interaction will complement and remain stable. However, if both play the Father role, there will probably be a power struggle and tension will arise.

# 2.1.2. Patient and medical staff adjustment

In recent years, the idea that the patient is passive and the health professional has the active decision-making role has been questioned (Arora & McHorney, 2000; Creer, Holroyd, Glasgow, & Smith, 2004). This has led to the development of the collaborative care paradigm, fostering patients' participation in decisions regarding their health and treatment (Creer et al., 2004). However, latest research reveals that not all patients wish or expect the same level of active participation (Arora & McHorney, 2000; Levinson, Kao, Kuby, & Thisted, 2005; Patel & Bakken, 2010). For example, a recent study shows that even though 96% of all patients want their physician to consult their opinion, 52% preferred that the final treatment decision was taken by the professional, and 44% didn't want to search for information about their illness on their own, relying only on the doctor's expertise (Levinson et al., 2005). In general, young and educated patients tend to prefer a more active role in their treatment, while there is evidence that some specific sub-cultures (e.g. Hispanic patients in the U.S.A.) prefer a more passive role (Arora & McHorney, 2000; Patel & Bakken, 2010; Zhang et al., 2011).

Emerging from the above, a new paradigm has been developing, one that emphasises the interactional fit between patient's preferences and characteristics, and the caregiver's communicational style and intervention techniques (Christensen, 2004). Similarly to what other authors have done in the psychotherapy field (beutler & Clarkin, 1990), it is stated that there is no universally ideal interactional style, being necessary to adapt to the patient's style. This way, these authors question the "patient-centered" collaborative paradigm, declaring that it's crucial to assess patients' expectations and preferences towards decision making, as well as his reactance level (Brehm, 1966). Reactance is understood as the need to protect our own autonomy by opposing other's orders or direction. So, more reactant patients, or

those who prefer being more active in the decision-making process, would benefit from caregivers' collaborative style. On the other hand, less reactant patients, and those who prefer a more passive decision-making role, would benefit by a more dominant or directive caregiver style (Cousin, Mast, Roter, & Hall, 2012; Jahng, Martin, & Golin, 2005; Kiesler, 2006; Madsen, McQuaid, & Craighead, 2009).

#### 2.2. Methods

# 2.2.1. Research Design

The design of this study is non-experimental, cross-sectional, exploratory, descriptive and comparative. Qualitative analysis were used in order to access patient's experience and subjective processes (Glaser & Strauss, 1967; Hill et al., 2005), with Grounded Theory procedures for constructing theoretical models inductively from the recollected data (Krause, 1995).

## 2.2.2. Sample

The sampling technique used was theoretical sampling (Wilmot, 2005), which means that the selection of the sample was intentional and iterative, choosing the characteristics of the future participants based on the analysis of previous interviews. From the analysis of the first interviews, we decided to have participants with different levels of adherence to the medical treatment, and also from the private and public health systems. Sample size was determined by the theoretical saturation criteria, in which data recollection continues until no new categories, concepts or dimensions emerge, so further data recollection doesn't generate new information about the main research questions.

The public health sample was selected from two primary care public health institutions in Santiago, Chile. The private health sample was selected using snowball sampling, recurring to the research team's personal networks.

- The inclusion criteria were: Arterial Hypertension diagnosis, between 25 and 80 years of age, at least 8 years of school education, being self-reliant, entering voluntarily the hypertension medical treatment program, being in treatment for at least a month, living in Santiago, having Chilean nationality, and requiring to make lifestyle changes as part of their medical treatment.
- Exclusion criteria were: Cognitive impairment, psychiatric illness, current comorbidity with acute illness.

For selecting participants with different levels of adherence to the medical treatment, it was necessary to operationalise these levels. After doing literature research and

consulting with different health-care professionals, the following adherence levels were defined:

- Optimal: Compensated arterial pressure (<140/90) in the last two health control sessions. Also, the patient is satisfied with his adherence to the different aspects of treatment (diet, drugs, exercise, others), without the need or desire to adhere more.
- Sufficient: Compensated arterial pressure in the last two health control sessions. Patient adheres partially, not as much as they would like or think they need.
- *Insufficient*: The same as the "sufficient" group, but their arterial pressure is not compensated (>140/90).
- Total dropout: They don't go to health control sessions for at least two years.
   They adhere minimally, if at all.

Also, a differentiation was made between people who continued to attend to health control sessions and those who have dropped out of the medical system. Both groups could take the drugs, eat according to the diet and/or exercise, but the second group has abandoned the health control sessions for at least two years.

According to these criteria, the final sample was as detailed in table 1:

**Table 1: Composition of the sample** 

Adherence level	Private health	Public health	
Optimal	7	8	
Sufficient	7	8	
Insufficient	9	8	
Total dropout	1	3	

Health control attendance	Private health	Public health
Attends	14	21
Dropped out	10	6

## 2.2.3. Data recollection instruments

All data was recollected using in-depth interviews to hypertensive patients, conducted by a 5 member research team (20 interviews by the main researcher, and

the rest by the remaining four researchers) . The interview guide was modified according to the analysis of previous interviews. It was semi-structured and had an episodic element. Also, it included an adherence interview form and, for the public health participants, a medical record.

- Patient interview: It explores in detail different episodes of patient-caregiver interaction (including physicians, nutritionists and nurses), milestones in the patient's history with the illness and the patient's coping strategies.
- Adherence interview form: This was a more structured part of the interview, designed to explore in detail the patient's adherence to different aspects of the medical treatment, and their perception that they should or should not adhere more (see appendix 1).
- Patient medical record: It contained data about patients' blood pressure levels, weight, and attendance to medical control sessions. It was used to triangulate the information reported by the patients themselves.

# 2.2.4. Data analysis

Data analysis followed the general guidelines of Grounded Theory and Consensual Qualitative Research (Hill et al., 2005; Strauss & Corbin, 2002): several judges throughout the data analysis process to foster multiple perspectives; consensus to arrive at judgments about the meaning of recollected data; one auditor to check the work of the primary research team; and cross-analyses of domains and core ideas. Also, all analyses were done using the transcripts and the video from the interviews, in order to include patients' non verbal communication. Qualitative research software was used to help the coding procedure (Atlas.ti 7 & Nvivo 9).

The relational nature of the study required the comparison of data between subsamples, not arriving only at global results. In order to do this, the following procedure was developed: (1) start the analyses with a list of initial domains, derived from the objectives and interview questions; (2) analyse each interview individually, coding domains from the initial list and also open to emergent topics; (3) in each interview, for each domain coded, select and edit a core idea that expressed what the patient said; (4) this continued until no new domains or core ideas emerged (theoretical saturation point), at which point a hierarchical list of categories was

completed, with domains and core ideas representative of the whole sample; (5) return to each individual interview and classify each patient according to the presence or absence of the different core ideas in all the domains and categories; (6) with each individual classified, cross-analysis to compare subsamples could be made. For example, comparing the optimal or sufficient adherence group to insufficient adherence or dropout group, relative to the presence of a specific patient-caregiver interactional pattern.

Finally, it's important to point out that although the analysis had the aim of inductively generating theory, it was also inspired and influenced by the theoretical background about resistance as a relational phenomenon, presented before.

# 2.2.5. Ethical considerations

In order to preserve participants' autonomy and confidentiality, all data was recorded using anonymous codes and not real names, only consenting adults were included in the study, and no personal information was shared with anyone except the interviewer and the main researcher.

#### 2.3. Results

First, two major types of prototypical patients that emerged from the cross-analysis findings are presented, according to their preference towards a more active or passive decision-making role in the medical treatment. Then, different patient-caregiver interactional patterns are described, associated with higher and lower adherence. The results section end with the presentation of emergent findings regarding how patients' implicit perceptions of the medical staff as authority figures influence their interaction with them.

# 2.3.1. Two patient positions regarding treatment control

Coherently with previous research (Beutler et al., 2002; Patel & Bakken, 2010), two major prototypical patients were identified, according to their preference towards a more active or passive decision-making role in the medical treatment. In this paper they were denominated *keeping control* (27 patients) and *giving up control* positions (17 patients). It's important to note that neither of these positions showed higher overall adherence. Also, they are somewhat dynamic. For example, a patient can show a keeping control stance towards his physician, and a giving up control position towards his wife. Also, in some cases (7 out of 51) the patient showed both positions in the interview.

# 2.3.1.1. Keeping Control Position

Patients who exhibit a keeping control position want to adhere "their own way", challenging caregivers' decisions and preferring to arrive at their own conclusions regarding their treatment. They tend to see themselves as strong and autonomous, not wanting to depend on others or to feel controlled. Often they have a hard time accepting the restrictions imposed by the chronic illness' treatment. They have high self-efficacy about their own coping abilities, and they fulfil the treatment indications when these are coherent with their own motivations and they agree that they are worth following. Facing difficulties with the treatment, they are more likely to drop out of the medical control sessions, and continue with a partial adherence on their own. An expression representative of them would be: *I don't need anyone to tell me what I can or can't do*.

# Patient 26, sufficient adherence

Patient: The first thing the doctor said to me was that I had to start a very "strict" diet, that made me reject it immediately, because so strict I'm not [...] so I'm going to try it like this, if it works I listed to myself, if it doesn't I'll listen to the doctor.

# 2.3.1.2. Giving Up Control Position

They prefer to adhere following the caregiver's indications "to the letter", trusting his decision-making criteria instead of relying on their own choices regarding the medical treatment. For them it's not difficult to ask for help, and they like to be taken care of by others. Also, for them it's not difficult to accept the limitations and restrictions imposed by the illness and its treatment. They sometimes lack self-efficacy about their coping abilities and can rely on others to guide and remind them in order to take action. When they face difficulties, they abandon aspects of the treatment, and if they drop out of the control sessions (which is not common), it's likely that they'll abandon the treatment completely. A characteristic expression would be: *I can't do this on my own, I need help and guidance*.

## Patient 21, Optimal adherence

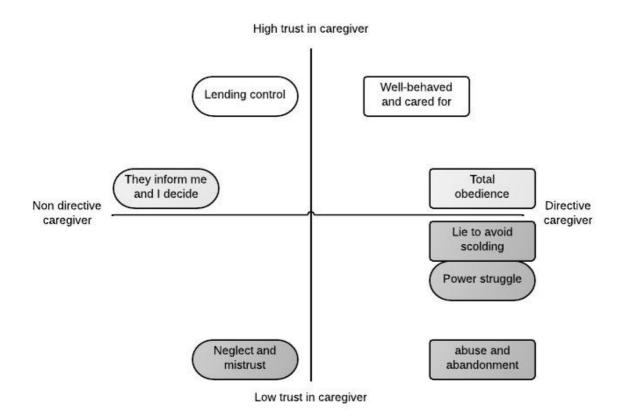
*P*: Yes, the doctor is very happy with me [...]. That helps me very much! [...]

P: [Regarding eating without salt] We put a little salt in it (laughs), you get bored without salt. And you have to follow the doctor's rules and that's it.

# 2.3.2. Different patients show different interaction patterns with caregivers

Analysing patients' reports of relational episodes with their caregivers, 8 different interactional patterns emerged, some associated with higher adherence than others, as shown in figure 1.

Figure 1: Different patient-caregiver interactions



Below these interactional patterns are presented in more detail.

# 2.3.2.1. Patients who keep control

# 2.3.2.1.1. Lending control

These patients, when they adhere optimally, establish a type of relationship in which they trust the medical staff and thus, voluntarily and conditionally, let them direct the treatment process. However, this is not unconditional or blind trust, because if they don't like something about the treatment, they reclaim control and adjust it or change caregivers. Also, this trust develops either because they know the caregivers very well, or because they have a positive transference to their institution. The caregiver is perceived as giving freedom, and occasionally as a friend.

# Patient 45, optimal adherence

P: No, I don't change the doctor's recipe [...] and if he changes the treatment plan I do as he says [...], I'm a good patient.

[...]

P: [Discussing about another physician] I didn't like her and just didn't come back [...]. For example he asked for a radiography, and he did it incompletely, and I, without being a doctor, said to her "doctor wouldn't it be better if you asked for both these tests immediately?" [...] Then she said "I know what I'm doing". "Yes", I said, "but I'm the patient".

# 2.3.2.1.2. They inform me and I decide

When the patient who keeps control does not have so much trust in the caregiver, he regards him as service provider, expecting a functional (not emotional or nurturing) relationship where the doctor provides information and the patient makes the decisions. Here the patient explicitly avoids positioning the caregiver in a hierarchically superior position. These patients' adherence is variable: sometimes it's optimal, but other times they seldom attend the health control sessions, only dint it because they need a checkup, or require adjusting the treatment.

As long as the caregiver shows a non directive stance and allows the patient to feel in control, the interaction can be functional. However, if the caregiver acts in a directive manner, there will probably be a power struggle and the patient will change health professionals or continue treatment on his own.

## Patient 50, optimal adherence

P: The doctor instructed me to have some exams taken, but because I have zero trust in doctors, I dismissed that one and now I'm being advised by another one [...]. I think that we hire consulting services because we are the ones responsible for our health. The doctor does not heal, does nothing [...]. If the doctor orders me to have heart surgery, for me it's an opinion, the decision is taken by me.

# 2.3.2.1.3. Power struggle

In this kind of interaction, patient and caregiver take part in a struggle where neither one wants to yield, as both think they should guide the treatment. This is a highly unstable position, because a power struggle erodes trust and so the patient will probably try to change caregivers or abandon treatment.

This pattern is usually generated when a mistrustful patient challenges the caregiver's decisions and authority. This arouses, in the caregiver, the desire to reaffirm his authority and justify the treatment decisions, creating a symmetrical escalade until the relationship is broken.

In cases where this vicious circle was avoided, the health professional took a non directive stance, giving freedom and listening to the patient's wishes and concerns, even when disagreeing with them. This way, if trust could be somewhat restored, the doctor could influence the patient in a "they inform me and I decide" kind of relationship.

#### Patient 42, insufficient adherence

P: There are people who go to the doctor because their nail hurts! [...] I try to avoid it at all costs! Even if I notice something, I see it and heal myself [...]. I fought with the doctor because he doubled my dosage, hoping that I, being reluctant as I am, would take half of it [...]. I told him why would I take more than enough if I'm OK, but he said "because when I check your blood pressure it's high". But it's not high, it's in the limit, 14/9 is not high, high would be 16, 15.

# 2.3.2.1.4. Neglect and mistrust

In these cases, the patient has lost hope that the caregiver can help him and thus stops attending, judging the medical staff does not meet his expectations, and it will be better to continue on his own. These patients in general wish to keep control (although this pattern could appear occasionally with patients who give up control) and want a doctor who can give them liberty, but also want a supportive and caring relationship. They feel disappointed when they feel the doctor does not consider their individuality or gives them the care they need.

This pattern is usually generated with patients who at the same time show reluctance towards the caregiver's instructions, and demand care and attention. Faced with this demanding attitude, the caregiver can become frustrated and withdraw his affection, letting the patient do as he wishes, which can be perceived as neglect by the patient,

reinforcing his critical stance towards health professionals. Alternatively, if the doctor responds in a directive manner, trying to control the patient, he can feel oppressed or mistreated and abandon anyway.

When this vicious circle was avoided, the caregiver could develop a trusting relationship, giving the patient enough time, care and attention, and letting him have the final word on treatment decisions. This requires much time and effort from the health professional.

## Patient 46, sufficient adherence

P: About the health controls I think I'm like... I don't know (laughs), I haven't attended in about 3 years [...] because I haven't felt it was necessary. I'll go there, the doctor will check the prescription and say "carry on doing the same", and it's 50.000 pesos or more [laughs].

[...]

P: In the end you don't feel treated as a person, they just deal with diseases [...]. So conflict I haven't had, never, but I get disappointed.

Interviewer: And what happened then, when that happened and you got disappointed?

P: I changed physician, I looked out for another one.

#### 2.3.2.2. Patients who give up control

#### 2.3.2.2.1. Well-behaved and cared for

This type of interaction appears more often in high adherence patients (although it also can be seen in insufficient adherence cases). Here, the patient does as he's told, and perceives the caregiver as a nurturing authority figure that provides support and appreciation. The patient feels that he can trust the caregiver, reporting his difficulties with the treatment. These patients are motivated by the professional's care and also they feel proud that the caregivers are happy about their good adherence behaviour.

#### Patient 16, sufficient adherence

I: And if you had some problem with that doctor, would you change to another doctor?

No, I think we'd need to talk, because I trust her a lot [...]. Even more, I've told her I've smoked, stopped smoking, there is trust, I mean, I don't go lying to her.

#### 2.3.2.2.2. Total obedience

In this kind of interaction, the patient feels he has no power or rights over the caregiver, showing a submissive attitude and also some mistrust, as he fears the consequences of showing any dissent. He doesn't expect warmth or special care, thinking he must do everything as he's told. This attitude is dangerous because it can generate resentment and lead to abandonment, either to avoid further mistreatment or because the patient can't continue adhering is such an inflexible way.

This pattern is generated when the patient perceives authority figures as dictatorial and is afraid of confronting them, expecting severe retaliation. Even though patients in this interactional pattern appear easy to deal with, they enable the caregiver to put himself in a controlling and authoritative position, increasing the chance of mistreatment and thus reinforcing the perception that they can't exert their autonomy and that authority figures are persecutory.

The only option to avoid this vicious circle is for the caregiver to avoid playing the role offered by the patient. This means actively asking the patient about his difficulties, doubts and needs, even if the patients persists in a submissive attitude. If the health professional validates dissent and manages to create a safe haven for the patient, the relationship can transform into one where the patient shows good behaviour and feels taken care of.

# Patient 28, dropout

For me, it's weird that they didn't ask me to take medication, because if I'm hypertensive I retain liquids. So if I don't take medication and I retain liquids, I'm afraid what will happen to my kidneys, but I can't, I'll never defeat a doctor. So if she said that, then I can't argue any more.

#### 2.3.2.2.3. Lie to avoid being scolded

In this interaction pattern, the patient does not express any difficulties or non adherent behaviour, either motivated by fear of being scolded or because he wants

to avoid arguing with the caregiver. In order to avoid this confrontation, he lies exaggerating his adherence, or avoids attending health control sessions, generating a vicious circle where non adherence produces more non adherence. This is an alternative way of dealing with the same situation as in the *total obedience* pattern, but here the patient releases inner tension and manages to avoid the feared retaliation or confrontation.

The patient appears submissive and well-behaved. The caregiver either doesn't explore possible difficulties enough, or starts scolding at the first sign of problems or disagreement. In order to break this vicious circle, the caregiver needs to assume a caring and validating stance.

#### Patient 28, dropout

The doctor, she was so harsh, she was like a cop. That woman, I remember I didn't go to her office anymore because I was afraid of her [...] She gave me a very strict, strict diet. I dropped, I swear, like 20 kilos, Good! I was frozen to death, with a terrible mood. I couldn't work [laughs] because I was scolding everyone, really! I even had to ask for a medical licence. Then I gained 8 kilos. I said: "I'm not going back because this woman is going to kill me (laughs). [...] Then I gained... now I'm about 30 kilos overweight.

### 2.3.2.2.4. Abandon to avoid further abuse

In these situations the patient drops out because, expecting care and protection, he feels attacked or mistreated by the caregiver. Consequently, dropping out is a way of protecting himself, and does not usually lead to autonomous adherence.

This interaction is generated when patients show mistrust, defiance and a negative view of authority (perceiving it as critical or persecutory). This defiant and neglectful attitude towards treatment probably generates frustration and annoyance in the caregiver, as well as desire to reinstate his challenged authority. This frequently leads to scolding, perceived by the patient as attacks and mistreatment, thus reinforcing his initial distrustful attitude.

The only way in which this vicious circle was broken was if the caregiver devoted time and effort exclusively to restoring trust and provide a safe haven with care and attention. Later, if trust was effectively reinstated, the patient could be open to receiving information and indications.

#### Patient 9, dropout

P: I haven't gone in over two years, I haven't consulted any doctor [...] the only doctor I saw was when I couldn't stand the pain in my knee. I cried in pain [...]. No doctor gave me a medical licence, I mean I had to keep walking and one even told me that "if I lost weight", with that tone, "if you lose weight and keep your mouth shut for one month and don't eat nothing you'll be much better". So obviously I said "get lost" and never returned.

[...]

So the truth is that I'm not very fond of doctors [...]. When someone insists with what I have to do I... I fight that and rebel [...] no matter who it is, I do the opposite.

# 2.3.3. Patients' implicit perceptions of caregivers as authority figures

One important emergent finding was that in some patients, there was a relational pattern in which one position (internalised, or personified on the caregiver) demands and criticises, and the other position rebels and refuses to comply (the patient, or another internalised part).

This "top dog - under dog" dynamic (Perls, 1976) was specially evident in poor adherence patients. They felt that they had no choice but compliance, faced with demands that were too high or too difficult. The demanding other (either external or internalised) was experienced as a critical and persecutory authority, that would retaliate at any sign of dissent or failure. Faced with this, some patients behaved submissively, others lied to avoid the feared confrontation, others protected themselves and their autonomy, while others fought defiantly or fled in order to protect themselves. Contrary to the research team's initial expectations, poor adherence patients showed more fear and self-criticism than minimisation or self-indulgence.

Patient 38, dropout

*I:* Why did you stop going to the doctor?

P: I didn't want to spend my whole life taking pills. I don't want to spend my whole life

thinking "you can eat this, can eat that". No! You can't eat that, leave it there!

Because many people are like that with people. Even my mom, "you can't eat this",
whenever my mom comes. I'm sick of it (laughs) So, I didn't want to live like that, I'd
rather die than live like that.

A sign that the patient had this internalised critical or persecutory authority figure was the appearance of a phenomenon denominated in this study **Mischievous Smile**. This takes place when a patient smiles or laughs when talking about his own non adherence behaviours, despite wanting explicitly to adhere. This phenomenon is similar to that has beed described as the "Gallows Transaction" (Berne, 1964). In this interaction, one person in a Child position laughs when revealing a provocation, looking for complicity (hoping that the listener positions himself also as a child that shares a mischief) or clemency (hoping that the listener, instead of acting like a critical parent, behaves as a nurturing one, forgiving the transgression). Based on the patients' behaviour, a third option emerged: that the laughter is a form of showing contempt and defiance to this critical parent figure. As this behaviour appeared in the context of a non normative, non judgemental interview, it's probable that this internalised critical authority figure is triggered implicitly just by talking about adherence.

On the other hand, higher adherence cases don't show the *mischievous smile* or this "top dog-under dog" dynamic. They don't adhere motivated by self criticism or perfectionism; instead they do it without feeling they need to make an impossible effort. These patients tolerate occasional noncompliance when adhering is too difficult, accepting their limitations or changing their caregiver if they didn't feel comfortable. They, despite claiming that they could adhere more and have better health, have reached a point where higher adherence has negative costs for their quality of life.

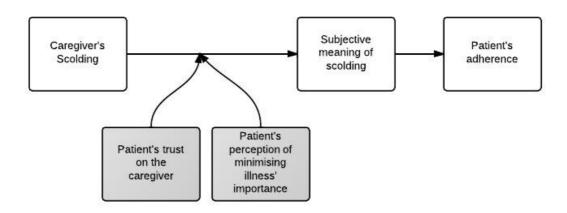
# Patient 6, optimal adherence

Now I'm not doing so much exercise. Before I went twice per week, but time has passed and now I feel tired [...]. Now I'm doing Tai Chi once a week with thirty year old girls so, it's harder than going twice a week with women my age [...]. Oh no, I'd rather sleep, I need to sleep.

# 2.3.4. Scolding as a double-edged sword

Another observation that emerged from the cross-analysis findings was the diverse effects and interactional meaning of the scolding patients receive from their caregivers when they show noncompliance. Two factors appeared to influence whether the scolding had a positive or negative effect, comparing the patients' reports of relational episodes (figure 2):

Figure 2: Trust and perception of minimising risks as requisites for scolding to have a positive effect



# 2.3.4.1. Positive impact: Scolding as a sign of caring and guidance

In these cases the patient has a trusting relationship with the caregiver, being open to his influence. The reprimand comes when the patient feels that he is minimising the risks associated with the illness, so serves to problematise the patient's behaviour. This way, it is experienced as a sign of caring and guidance, and its absence would be taken as indicating lack of interest and neglect.

#### Patient 47, sufficient adherence

I: And when he has reprimanded you, how is that for you, what happens?

P: At first you are angry that someone you're paying is scolding you. But then you take it like "shit, but this guy in the end is saving my life".

# 2.3.4.2. Negative impact: Scolding as a sign of unjustified and unacceptable authoritarianism

In these situations, the patient (usually in a keeping control position) has a specific idea about the treatment and the doctor does not agree with it, demanding something the patient doesn't want. This is perceived as an expression of authoritarianism, leading to a power struggle or dropout, either because the patient feels he can continue better alone, or in order to avoid confrontation. In other cases, the patient feels as if he's doing the best he can (not minimising) and has a diligent and self-sacrificed self-concept. Thus, the reprimand is perceived as unjustified and not recognising the patient's efforts.

# Patient 41, insufficient adherence

P: I was going to a good physician [...] but I think he was mistaken in the end. He asked me for some exams that I didn't take, so I don't want to go back [laughs] and say again "look doctor, I didn't take those exams" [...]. I think I told him I didn't think they were necessary, they were too invasive, but he said "well, who's the doctor, you or me, ah? [laughs]. So, of course, after something like that I can't go back as tell him "look, to tell you the truth I didn't listen to you".

#### 2.4. Conclusion

# 2.4.1. Synthesis of main findings

First it was shown how patients can be classified into two groups, according to whether they wish to keep or give up treatment control. It was observed that a caregiver's directive style associated better with a patient that gives up control, and a non directive style was better with a patient that keeps control. Then, different interactions between caregivers and both patient prototypes were analysed, and it was shown how some of them associated with better adherence than others. Finally, emergent findings were presented, suggesting that patients' implicit perception of the caregivers as authority figures plays a key role in their adherence to treatment.

# 2.4.2. Discussion

The findings presented in this paper support previous ideas about the necessary fit between the intervention's directiveness and patient's expectations and style regarding treatment control (Christensen, 2000). This is an important issue for health professionals to assess, for example using self-report questionnaires like the Control Preferences Scale (Degner, Sloan, & Venkatesh, 1997), the Participant-Practitioner Orientation Scale (Krupat et al., 2000) or the Therapeutic Reactance Scale (Dowd, Milne, & Wise, 1991). From a methodological point of view, these findings suggest that it's necessary to recollect both patient and intervention data and analyse them together for possible interaction effects. This would allow researchers to analyse the specific effect of different types of interventions or caregiver styles on different types of patients, and not only the main effect of different interventions on all patients indistinctly (Christensen, 2004).

Additionally, it's important to notice if the patient comes to the caregiver with a trustful or reluctant disposition. If the patients shows initial mistrust, with an internalised persecutory or critical authority figure, the health professional can easily reinforce a vicious circle that leads to negative interactions such as a *power struggle*, *total obedience*, *lying to avoid being reprimanded*, *neglect and mistrust* or *abandon to avoid further abuse*. In these cases, before exercising disciplinary actions such as reprimanding or reminding the patient of the risks of non adherence, it's necessary to restore trust in the relationship and get the patient to perceive the caregiver as a

nurturing -not critical- parent. Patients often relate to doctors in an analogical way as they relate to other authority figures, and as described in parent-child relationships (Baumrind, 2012), authority not supported by a trusting bond fosters rebellion or disempowerment.

Finally, this relational perspective rejects value judgments like the ones implicit whenever one describes a patient as "resistant", "non adherent", "uncooperative" or "self-defeating". This perspective understands successful adherence as the product of the interactional system as a whole, and that doesn't entail 100% "to the letter" adherence, but a particular and sustainable adaptation to the patient's needs and possibilities. In the psychotherapy field there is wide consensus on the importance of patient-therapist agreement on the goals and tasks of the therapeutic process, regarding it as a key predictor of therapeutic outcome (Santibáñez et al., 2009). However, in the medical health field this goes against what people imply when they talk about treatment adherence or cooperation. These expressions suggest that there is only *one* treatment, *one* goal (and that is 100% adherence), and varying degrees of fulfilment. This study's findings suggest that this way of defining adherence and the treatment goals is harmful to the patient-caregiver bond and has a negative effect on treatment outcome. Accordingly, this alternative perspective could help break the vicious circle of demands and rebellion that erodes both caregivers and patients.

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# Appendix 1: Adherence interview

**Introduction**: "When you have an illness or go to the doctor for some problem, it's usual that you are given some indications for medication, diet, exercise, etc. Many times things happen that make us adjust those indications and change them, and in the end it's common that we follow the indications in a different way than how we talked about them with the doctor. We want to know about your experience, what did you talk initially with the medical staff and what have you done in your everyday life".

**Instructions for interviewer**: Build *rapport*. Ask with implicit forgiveness and no implicit value judgements. For example: "could you?", "what difficulties have you encountered?", "when was the last time you couldn't take the medication?". It's better to assume that the patient didn't do it, than force a confession. Never ask "did you do X?".

Complete the following table: First ask the patient about the specific instructions that the doctor indicated, for each treatment aspect. Then, complete the table with the appropriate percentage, with "100%" meaning following doctor indications "to the letter".

**Table 2: Adherence interview** 

Aspects of treatment	Real % (according to	Wished % (by the patient)	Expected % in the future
	patient)		(by the patient)
Health control attendance			
Medication			
Diet			
Exercise			
Alcohol, tobacco, etc.			
Others: Mealtimes, rest,			
sleep			

# 3. Conflict and ambivalence in chronic illness patients with high and low adherence to medical treatment. A dialogical self analysis

Author: Pablo Herrera S.

#### **Abstract**

Patients' low adherence to medical treatment in chronic illnesses is one of the biggest public health problems. Numerous studies have helped understand different factors associated with patient adherence. However, these theoretical models have not been able to fully explain the ambivalence of those patients who ask for medical assistance, but nevertheless fail to follow the treatment as agreed. For this reason, these models fail to suitably predict patients' future behaviour, only predicting their conscious intention to adhere. This study aims to understand this ambivalence using dialogical self theory and qualitative research methods. 51 hypertensive patients were interviewed in order to explore their anti and pro adherence voices. The main values associated with nonadherence were: self esteem, autonomy, affiliation, wellbeing, freedom, health, or feeling that the extra effort is not worth it. Finally, almost all patients had both pro and anti adherence voices, and they used different implicit strategies to resolve their ambivalence: integration strategies allowed both voices to express themselves and be heard, and was associated with higher and more stable adherence. On the contrary, domination strategies aimed to reject or dismiss one of the voices, and were associated to poorer or less stable adherence.

Key Words: Dialogical self, resistance, chronic illness, adherence

#### 3.1. Introduction

Poets, economists and psychotherapists have long since wondered why some people seem to behave against their own best interest (Ariely, 2008; Beutler, Rocco, & Moleiro, 2001; Freud, 1958; Whitman, 2012). Investing time and money in a treatment and then not cooperating fully with it (or actively sabotaging it), holding on to harmful relationships, paying for a monthly fee in a gym and not exercising, are just a few of the many examples of human contradiction. This phenomenon has been understood as self-sabotage, repetition compulsion, death wish or simply irrational behaviour (Kurzban, 2011). In psychotherapy, patients who seem uncooperative have been called resistant, reactant, oppositional, noncompliant or intractable (Beutler, Moleiro, & Talebi, 2002). Common to all these concepts is the observation that sometimes we have strong motivations to change, but we don't do what we need to do to implement that change.

This paper aims to explore this "resistant" behaviour focusing on a group of people who have very powerful motives to change their behaviour: people with chronic illness, specifically Arterial Hypertension (HT). Chronic illnesses' prevalence has been rising (for example, in western countries HT has a 20% prevalence, and higher in older population), and their treatment focuses on changing patients' lifestyle and habits (World Health Organization, 2003), thus increasing the importance of patients' active participation (Creer, Holroyd, Glasgow, & Smith, 2004). Even though treatments are usually effective, patient adherence is low, around 30–60% for medication and lower for diet and exercise (Martin, Williams, Haskard, & Dimatteo, 2005). This has motivated a large amount of research in patient non adherence, which has been conceptualised as a complex process that includes patient, health professional, health system, illness and therapy factors, such as patient self-efficacy, problem awareness and information about the illness; treatment complexity and dosage; visibility of symptoms, etc. (Meichenbaum & Turk, 1987; World Health Organization, 2003)

However, traditional adherence research has not been able to predict patients' adherence behaviour, only estimating their intention to adhere (Christensen, 2004). Also, the intervention programs aimed to improve patient adherence are very complex and only have moderate effects (Haynes, Yao, & Degani, 2005). We think

that in order to contribute to adherence research, some methodological and theoretical limitations need to be addressed. (a) Methodologically, traditional research uses mainly self-report methods to assess patients' conscious and rational intentions, beliefs and attitudes towards the treatment and illness (Lehane & McCarthy, 2007; Lubaki, Mabuza, & Malete, 2009; Marx et al., 2011; Pound et al., 2005). However, rational and conscious intentions don't explain fully nor predict future behaviour change (Webb & Sheeran, 2006; Westra, 2011). (b) Theoretically, most studies that analyse ambivalence proclaim that its presence at the beginning of treatment is a strong predictor of patient dropout (Brogan, Prochaska, & Prochaska, 1999; Prochaska, DiClemente, & Norcross, 1992), but don't explain how patients resolve their inner conflict, just stating that at some point in the change process the pros of change outnumber the cons (Prochaska et al., 1994). Also, except for the motivational interviewing technique, most intervention programs don't consider the importance of the anti adherence voices (Britt, Hudson, & Blampied, 2004). All of this means that implicit and not easily conscious processes are left out of most research projects, it's not yet fully understood how patients resolve their ambivalence, and in general, interventions don't consider the importance of the anti adherence or resistant voices, just focus on empowering the *pro adherence voices*.

Aiming to contribute to the understanding of patients' non adherent or resistant behaviour, this paper defines noncompliance as a manifestation of inner ambivalence, implying coexistence of both *pro* and *anti adherence positions* in the same person (as will be explained in the following section). Coherently, the aim of this paper is to explore Hypertensive patients' *anti adherence positions* and describe how they deal with their ambivalence between *anti* and *pro* adherence voices, relating this with their adherent or non adherent behaviour. This ambivalence will be understood as resistance from a dialogical self perspective (Hermans, Kempen, & Van Loon, 1992), and to our knowledge this is the first study to address empirically, with a relatively large sample (51 patients), their anti treatment voices and the strategies they use to resolve their ambivalence.

#### 3.1.1. The Self as Multi-Voiced

Contrary to common sense belief, many theoretical models view the self as devoid of a central core, instead being composed of different parts, positions, modules, subpersonalities or voices (Dimaggio, & Stiles, 2007; Hermans et al., 1992; Honos-Webb & Stiles, 1998; Kurzban, 2011; Lester, 2007; Rowan, 2010). In these conceptualisations, dissociation and incongruence between different voices is not seen as a phenomena only present in pathology, but instead as a normal feature of human experience and brain evolution (Kurzban, 2011; Rowan, 2010). Also, different positions in the dialogical self can each have their own wishes, feelings, memories and resources (Hermans, 1996), even if they are rejected or non consciously accessible by more dominant parts in the self's community of voices (Gonçalves et al., 2011). Finally, these voices are activated in a specific time and experiential context, so in one moment a *pro adherence* voice can be salient and dominating, and in another an \*anti adherence \*voice can have control (Hermans, 2003; Valsiner, 2002).

Most theoretical models utilised to understand medical non adherence regard it as a problem behaviour, something that must be fought against, caused by irrational biases and beliefs (Beutler et al., 2002; Levensky, 2006). On the contrary, from a multivoiced understanding of the self, when change is desired consciously but not happening (assuming the person has the necessary resources for change to occur), there may be more than one internal voice operating; one that moves toward change and another one opposing it (Engle & Arkowitz, 2008). What to do once this ambivalence is acknowledged? From this perspective it's not enough to empower the explicit pro change voice (the only one usually known to researchers, practitioners, and even consciously to the patient himself). For lasting change to occur, these implicit anti-adherence voices should not be rejected or fought, but acknowledged, integrated or assimilated (Hermans et al., 1992; Honos-Webb & Stiles, 1998). This is because resistant or anti change behaviour is seen as an adaptive response, the best available option in that particular experiential context, considering presently activated voices, schemas and personal resources (Arkowitz, 2002; Ecker & Hulley, 1996). Therefore, fighting the 'resistant' or 'anti adherence' voice would generate more resistance, while acknowledging and accepting it could open possibilities for cooperation and change.

In health psychology there are few studies that explore patients' anti adherence voices. Motivational Interviewing emphasises the importance of exploring patient

ambivalence and has been applied to different health related problems (Britt et al., 2004). Also, Dialogical Self theory studies have recently been used to understand subjective meaning and internal voices on teenage patients with Chronic Fatigue Syndrome (van Geelen, 2010). Other qualitative studies have explored why chronic illness and specifically HT patients don't adhere to medical treatment, from their own perspective. Some of the main reasons fon noncompliance patients give are: concerns about the adverse effects of medication, about the stigma associated with some illnesses, fear of dependence to treatment, distrust towards medical doctors and institutions, and also the perception that their problems were not too severe (Lukoschek, 2003; Pound et al., 2005; Unson et al., 2003; Viswanathan & Lambert, 2005). Accordingly, it's important to remember that when patients don't adhere it's not only because they failed to do so, but also because they *intentionally* chose not to (Lehane & McCarthy, 2007).

One crucial difficulty in applying the multivoiced self metaphor to the study of ambivalence and nonadherence is the methodology for exploring pro and anti adherence voices. Discussing self-report questionnaires, Rowan (2003) asks how can personality tests be valid if there is more than one sub-personality in the same person. If different and often contradictory information can be collected from the same person in the same investigation, and the assumption of the unified and solid self is challenged, what happens to our methods of collecting information? (Hermans, Rijks, & Kempen, 1993; Rowan, 2010). Furthermore, if researchers or clinicians want to understand the anti adherence voice it is necessary to access it, and not only the pro adherence voice. Miller and Rollnick's Motivational Interviewing (2002) aims to evaluate empathically both pro and anti change motivations, but the difference is that the multivoiced self view of voice emphasises unconscious or implicit constructs and schemas. These implicit schemas are, by definition, very difficult to explore via direct self-report measures or interviews directed only towards conscious and rational-level contents. In this regard, Ecker & Hulley affirm that patients can become aware of their unconscious positions, but that requires appropriate interview and exploration techniques (1996).

## 3.1.2. Ambivalence in the change process

Prochaska's transtheoretical model of change states that when people are in the precontemplation stage, they don't perceive a problem, or the cons of change far outweigh the pros (Prochaska et al., 1994). People start having motivation to change in the next stage, contemplation, when the cons and pros of change are of almost equal importance, and the person experiences intense ambivalence. Research has shown that in following stages of the change process, there are still cons of change, but in successful cases the pros eventually outweigh them (Di Noia & Prochaska, 2010).

Dialogical self theories assert that if these voices or positions refer to the same object or theme (e.g. Adherence), they must have some semantic relation: they can be opposed, aligned, one an intensification of the other, etc. {Salgado:2011vq}. When they are opposed, there is the potential for ambivalence. Several models describe and analyse the different ways in which opposing voices can interact within the self, resolving or maintaining ambivalence and conflict. In general, it is said that exclusive dominance of one part of the self over all others is problematic, and that an aim of therapy should be to help patients be aware and acknowledge parts of the self previously in the shadows (undefined author et al., 2007). For example, Stiles' Assimilation model states that when a voice is not accepted into the dominant community of voices of the self, it becomes problematic and arises in symptomatic or conflicting ways (Honos-Webb & Stiles, 1998). Empirical research based on this model has shown that in successful cases, a problematic, unwanted voice establishes dialogue with the community, negotiates an understanding, and is assimilated into the community, becoming a resource (W. Stiles, 2001).

Valsiner (2002), from a theoretical perspective, describes several ways in which ambivalence between several voices can be regulated. Expanding on these concepts, Gonçalves et al (2011) showed that psychotherapy patients in unsuccessful cases display ambivalence towards change, and they resolve this ambivalence minimising or deprecating the *pro change* voices, reinstating temporarily the dominant *anti change voice* in order to avoid inner discrepancy and uncertainty. However, this trivialisation of *pro change* voices does not suppress them completely, eventually returning to the same sequence and showing oscillation in which these

opposing voices (or *i-positions*, as the authors call them) dominate the self alternately, in a negative feedback loop that Valsiner has called 'mutual in-feeding' (2002).

#### 3.2. Methods

# 3.2.1. Research Design

The design of this study is non-experimental, cross-sectional, exploratory, descriptive and comparative. Qualitative analysis were used in order to access patient's experience and subjective processes (Glaser & Strauss, 1967; Hill et al., 2005), with Grounded Theory procedures for constructing theoretical models inductively from the recollected data (Krause, 1995).

## 3.2.2. Sample

The sampling technique used was theoretical sampling {Wilmot:2005wc}, which means that the selection of the sample was purposive and iterative, choosing the characteristics of the future participants based on the analysis of previous interviews. From the analysis of the first interviews, we decided to have participants with different levels of adherence to the medical treatment, and also from the private and public health systems. Sample size was determined by the theoretical saturation criteria, in which data recollection continues until no new categories, concepts or dimensions emerge, so further data recollection doesn't generate new information on the main research questions.

The public health sample was selected from two primary care public health institutions in Santiago, Chile. The private health sample was selected using snowball sampling, recurring to the research team's personal networks.

- The inclusion criteria were: Arterial Hypertension diagnosis, between 25 and 80 years of age, at least 8 years of school education, being self-reliant, entering voluntarily the hypertension medical treatment program, being in treatment for at least a month, living in Santiago, having Chilean nationality, and requiring to make lifestyle changes as part of their medical treatment.
- Exclusion criteria were: Cognitive impairment, psychiatric illness, current comorbidity with acute illness.

For selecting participants with different levels of adherence to the medical treatment, it was necessary to operationalise these levels. After doing literature research and

consulting with different health-care professionals, the following adherence levels were defined:

- Optimal: Compensated arterial pressure (<140/90) in the last two health control sessions. Also, the patient is satisfied with his adherence to the different aspects of treatment (diet, drugs, exercise, others), without the need or desire to adhere more.
- Sufficient: Compensated arterial pressure in the last two health control sessions. Patient adheres partially, not as much as they would like or think they need.
- *Insufficient*: The same as the "sufficient" group, but their arterial pressure is not compensated (>140/90).
- Total dropout: They don't go to health control sessions for at least two years.
   They adhere minimally, if at all.

Also, a differentiation was made between people who continued to attend to health control sessions and those who have dropped out of the medical system. Both groups could take the drugs, eat according to the diet and/or exercise, but the second group has abandoned the health control sessions for at least two years.

According to these criteria, the final sample was as detailed in table 1:

Table 1: Composition of the sample

Adherence level	Private health	Public health
Optimal	7	8
Sufficient	7	8
Insufficient	9	8
Total dropout	1	3

Health control attendance	Private health	Public health
Attends	14	21
Dropped out	10	6

# 3.2.3. Data recollection instruments

All data was recollected using in-depth interviews to hypertensive patients. The interview guide was modified according to the analysis of previous interviews. It was

semi-structured and had episodic elements. Also, it included an adherence interview form and, for the public health participants, a medical record.

- Patient interview: It explores in detail different episodes of patient-caregiver interaction (including physicians, nutritionists and nurses), milestones in the patient's history with the illness, his coping strategies, and also utilises clinical interview techniques for exploring pro and anti-treatment motivations and implicit schemas (see appendix 1).
- Self-Report short questionnaire: At the end of the interview, there was an interviewer-administered short self-report form, focused on the more conscious perceptions of the patient about his motivations and abilities to adhere (see appendix 2).
- Adherence interview form: This was a more structured part of the interview, designed to explore in detail the patient's adherence to different aspects of the medical treatment, and their perception that they should or shouldn't adhere more.
- Patient medical record: They contained data about patients' blood pressure levels, weight, and attendance to medical control sessions. It was used to triangulate the information reported by the patients themselves.

# 3.2.4. Data analysis

Data analysis followed the general guidelines of Grounded Theory and Consensual Qualitative Research (Hill et al., 2005; Strauss & Corbin, 2002): several judges throughout the data analysis process to foster multiple perspectives; consensus to arrive at judgements about the meaning of recollected data; one auditor to check the work of the primary research team; and cross-analyses of domains and core ideas. Also, all analyses were done using the transcripts and the video from the interviews, in order to include patients' non verbal communication. Qualitative research software was used to help the coding procedure (Atlas.ti 7 & Nvivo 9).

The relational nature of the study required the comparison of data between subsamples, not arriving only at global results. In order to do this, the following procedure was developed: (1) start the analyses with a list of initial domains, derived from the objectives and interview questions; (2) analyse each interview individually,

coding domains from the initial list and also open to emergent topics; (3) in each interview, for each domain coded, select and edit a core idea that expressed what the patient said; (4) this continued until no new domains or core ideas emerged (theoretical saturation point), at which point a hierarchical list of categories was completed, with domains and core ideas representative of the whole sample; (5) return to each individual interview and classify each patient according to the presence or absence of the different core ideas in all the domains and categories; (6) with each individual classified, cross-analysis to compare subsamples could be made. For example, comparing the optimal or sufficient adherence group to insufficient adherence or dropout group, relative to the presence of a specific patient-caregiver interactional pattern.

The initial domains used for coding the interviews were: anti-treatment voice (any expression that had, to the patient, a negative association with adhering to treatment); pro-treatment voice (any expression that had a positive association); and level of adherence (optimal, sufficient, insufficient, and dropout, as defined earlier). Emergent domains represented the different implicit or explicit strategies for coping with the simultaneous presence of anti and pro treatment voices.

Finally, qualitative analysis was complemented with descriptive statistics, to give readers a better view of the distribution of categories within the sample. Following CQR recommendations, the following frequency labels were used (Hill et al., 2005): *General* for all but one of the cases; *Typical* for more than half and less than general; *Variant* for more than two and less than typical; and *Rare* for less cases.

#### 3.2.5. Ethical considerations

In order to preserve participants' autonomy and confidentiality, all data was recorded using anonymous codes and not real names, only consenting adults were included in the study, and no personal information was shared with anyone except the interviewer and the main researcher.

#### 3.3. Results

Almost every interviewed patient (96%) showed presence of both anti and pro adherence voices. However, it wasn't methodologically easy to explore those voices. So, in the following paragraphs, an explanation of the method used in this study to explore them will be provided (in section 3.1). Subsequently, the content of the patients' main *anti treatment voices* will be presented, according to their subjectively perceived value (section 3.2). Finally, the different interactions between *pro* and *anti* voices will be introduced, focusing on the different ways patients resolve their ambivalence towards change (Section 3.3).

# 3.3.1. The development of a methodology for exploring implicit anti-adherence voices

One of the first findings in the early stages of the study was that during the same interview it was possible to "hear" the *pro* adherence voice in one moment, and in another moment the anti adherence voice. Also, many times the patient seemed unaware of the *anti* voice, like he had forgotten what he had just said. Also, when the interviewer used more direct or implicitly judgmental questions (e.g. "Why don't you follow the doctor's indications?", or "do you think the benefits of adhering are worthwhile?"), the *anti* adherence voice seemed to hide, and only the *pro* voice became available. On the contrary, when the interviewer used other more indirect and non-normative questions (see Appendix 1), the *anti* voice was consciously available for the patient, and the previously "irrational" behaviour of the patient seemed understandable to the interviewer.

It was necessary to make sure that the interview methods used were appropriate for exploring the more implicit anti adherence voices and schemas. Otherwise, the most common answer would be some sort of excuse or rationalisation, as it's been proven that people tend to invent reasons for their own behaviour when they can't make sense of it (Kurzban, 2011). Other more indirect methods to explore these implicit positions have been developed in psychotherapy settings (Ecker & Hulley, 1996), so the research team faced the challenge to adapt these methods to be able to use them in a research (not clinical) setting. It's presented here thinking it can be useful for other researchers and clinicians.

For developing the method, there were at least three requisites: (1) There had to be a climate of empathy and rapport towards patients and their anti change voices, trying explicitly to avoid any normative attitude (Bogdan & Taylor, 1987). (2) Cognitive science and evolutionary psychology have shown that the brain has evolved to respond coherently with a specific context and state of the organism, not according to global attitudes or beliefs (Kurzban, 2011), which is a similar assertion than what dialogical self theories say about voices being specific in time and context (Hermans, 2003). (3) According to the psychotherapeutic principles of coherence therapy (Ecker, Ticic, & Hulley, 2012), it was necessary to access the *voice* or *position* for which not adhering was more important or valuable than adhering (the *anti adherence position*).

Based on these antecedents, the method developed and used in this study has the following steps:

- 1. Create a relational climate where it's allowed to express reluctance to adhere, and people won't feel judged.
- 2. Identify specific moments and situations in which the patient does not adhere.
- 3. Guide the patient to remember one of those moments, evoking it with detail until the patient can, experientially, transport himself to that moment, so he is aware of that specific context, emotions, and overall state.
- 4. Without leaving that specific context, guide the patient to experientially explore what would have happened if he had done what he "should" have done (what, in concrete terms, would have meant to adhere in that specific context). This has to be very concrete and specific regarding to what would have happened to the patient and to the people in that context, if present. Alternatively, ask the patient what kind of person acts like that in the same situation.

Although this obviously is not the only method to explore implicit anti adherence positions, it worked and only took few minutes to use during the interviews. After step 4, it was very easy to understand what positive value the "resistant" behaviour had for the patient. Also, this method can be used as a qualitative interview technique in a research setting, but also in a psychotherapy setting, as a clinical diagnostic technique, and as part of an intervention technique.

## 3.3.2. Anti adherence voices & their adaptive function.

In the following paragraphs, patients' main *anti adherence voices* will be presented, according to their subjective meaning or adaptive function.

#### 3.3.2.1. Self-Worth.

For half of the HT patients in the sample (51%), specially younger ones, it is difficult to assume that they are ill or in need of special care. They associate having hypertension and adhering fully to being hypochondriac, being "different" from the rest, being old, and not having enough strength to cope and carry on. Implicit in their dialogue is the assumption that only very sick, old or weak people need care. They don't adhere to different aspects of the treatment: sometimes the diet, exercise, medication, or they skip medical control sessions (for example, to avoid getting another adverse diagnosis).

# Patient 39, Sufficient adherence

Interviewer: You were telling me that you have a lot of courage, you are very good at tolerating pain and you only ask for help when the situation is serious. Do you know people who don't have so much grit, or that get frightened after a small alarm, or ask for help?

Patient: Weak people [...] I think those people are expecting others to do everything for them. I'm a Taurus, I'm very much associated to my sign, I'm like (laughs) a bull, with maybe too much endurance. My husband is a weakling. 'Ay, he says, I cut myself', but nothing happened to him.

Reinforcing the importance of assuming illness and needs in an acceptable way, participants with lower adherence generally didn't validate their own needs or assume their vulnerability. On the contrary, those with higher adherence tended to validate their needs and vulnerabilities.

## 3.3.2.2. Anxiety regulation.

Other HT patients (27%) have difficulties regulating their anxiety and distress, so they use food as a coping mechanism. In these cases, adhering to the diet part of the treatment would mean increasing their anxiety. They often take their medication, but don't adhere fully to the diet.

## Patient 31, Sufficient adherence

I: Do you have anything to tell me about your diet attempts? Because I've heard you say that you've tried several times to lose weight but it doesn't work and you don't know why.

P: Yes, the thing is, my work is very stressful, and I don't drink, don't smoke, and so my only way to cope with anxiety is eating. So, I have a struggle, either I kill myself with stress or I reduce it eating, and on the other hand I want to lose weight. But if I start smoking like before, when I smoked two boxes a day, I think it's better to be a little fat than start smoking, so there are other forces at stake.

# 3.3.2.3. Wellbeing.

Most patients (67%) associate some aspects of the treatment to lowering their quality of life, enjoying less, having an overly restrictive lifestyle, eating tasteless food, and being completely stressed with having to worry and control their desires all the time. A subgroup of these patients face the following paradox: in order to control their HT they need to worry about what they eat and their habits, but that stresses them out, and stress in turn makes their blood pressure go up. Also, adhering is associated with being like the military, too strict or extreme, and giving up on the pleasures of life, thus making life not worth living. These patients often take their medication but don't adhere too much to the diet and exercise part of the treatment.

# Patient 46, Insufficient adherence

I: And what do you think about people that are very strict with their food, exercise and all that?

P: From my point of view, they are strict, have organised schedules. I think sometimes, for example, they complicate themselves over small things. Sometimes they have the solution right beside them but because they are so strict, they don't see it [...]. I have a friend like that, she is rigid, like the military [...]. Some of them are hypochondriac [...] it's like being too serious, being afraid of normal stuff you know? [...] Like my parents, I'm, interested that they have quality of life, ok? If you're gonna live 50 years, I want you to live them well. It's no use to live 90 or 100 years if you're gonna live like shit, you know?

# 3.3.2.4. Affiliation.

For some patients (41%), adhering to the treatment means setting themselves apart from other people, distancing and sharing less. For most of these patients, adhering more is associated with not caring for others, for example making their family cook without salt; for others, being ill is the only way of being taken care of by others; and for the rest of this group, adhering means that they can be excluded from their group, or sharing less time with their family. For most of these patients, taking care of themselves means caring less for others, and they tend to prioritise the rest. They often take the medication, but adhere less to the diet or exercise.

## Patient 37, dropout

I: So you think that if you follow the diet, it could have an effect with your friends? What would happen if you arrive at a barbecue, for example?

P: (laughs) It depends, but its absolutely real that if you come to a group where everyone eats meat, and you come with your little lettuce, you allow them to mock you. Now, are you strong enough to tell them to go fuck themselves and say "I'm going to eat my little lettuce and if you don't like it you can get lost"?

#### 3.3.2.5. Freedom.

Just about half the patients in the sample (53%) associate adhering to the treatment with losing their freedom, living with too many prohibitions and becoming dependant on the treatment or the medical staff. They often place great value on their independence and their ability to do things on their own, with "no one telling them what to do". Usually they "forget" to take their medication, or avoid going to the medical control session.

#### Patient 30, Sufficient adherence

I: Is there anything that has hindered, or made treatment more difficult?

P: The most difficult part was at the beginning right? Eating without salt, and taking two pills a day, I think when I forgot to take the pills it was voluntary omission (mischievous smile) [...] Also, before it was like an obsession to check my blood pressure. I did it because the doctor asked, until I stopped doing that too because it was like slavery, to be checking my blood pressure every day.

Eventually I felt that one week, 10 days could pass by, and I didn't check it, so I wasn't enslaved by the little device.

## 3.3.2.6. Health (protecting from introgenic effects).

Also around half the sample (57%) have fears or have had direct experience of iatrogenic effects from the medical treatment. Some of them report having felt mistreated by medical staff, fear becoming addicted to the drugs, or suffering side effects not only from the medication, but also from the diet and exercise (for example changes in mood, or less energy). In general they care about their health, but have concerns about the specific treatment, often preferring less invasive or more natural alternatives. Some of them adhere reluctantly, but others, who maintain more control over their treatment, simply change the indications and do what they think is best.

### Patient 42, Insufficient adherence

P: It was 10ml Enalapril, afterwards he upped the dosage to 20ml, and it's twice a day so that means 40ml, so I think it's too much, so I only take 20ml, but I take care of myself in other ways, I mean I lead a healthy life, I don't drink or party and as I said I try to look for positive elements, for example chia seeds.

P: [...]

P: Some people go to the doctor because their nail hurts [...] I: I try to avoid [going to the doctor] at all costs! Even if I see something weird, I study it, I see it and I heal myself. [...] Because only one knows our own weaknesses [...] and besides one hears so many stories of malpractice.

#### 3.3.2.7. Lack of motivation to adhere more.

Finally, some patients don't adhere because they lack motivation to adhere. In their case, it's absence of pro change voices, not presence of anti change voices, that drives them to noncompliance. There are two sub-groups:

#### 3.3.2.7.1. It's not necessary to make the effort

Most of the patients (75%), even though they don't adhere fully, state that they don't need to adhere more (to some aspect of the treatment), meaning that the benefits of adhering more are not enough to justify the extra effort. Many times they believe that they are just fine as they are, and if they felt worse they would adhere more. Other

times they think that the treatment can't help them, for example because their HT is caused by stress, and the treatment does not help with that. They usually don't adhere to the more difficult parts of the treatment, specially diet and exercise, and sometimes going to the medical control session.

Patient 48, Insufficient adherence

I: So he told you to go to the health control every so often, right?

P: Yes, I don't know, every 6 months, but I haven't gone, because I haven't felt bad, so [...]

I: And how was it for you when you were told you had hypertension? How did you react, what did you think?, what did you do?

P: Well, I said, it's part of human nature because these things must come at some point, for some it's hypertension, for other cholesterol, for others it's the heart. I mean, it's age, for some this happens at 60, for others at 65, 70, something, some ailment you have to suffer when you get to a certain age. So I take it with ease, and you need to learn to live with your physiological deficit because that's how aging is.

### 3.3.2.7.2. It's too heavy a burden for me

This voice is characterised by hopelessness, and is present on a group of patients (25%) that feel as though coping with the illness and doing all the lifestyle changes asked from them, is too heavy a burden for them to face. Some are facing depression, others are so afraid of the diagnosis that they are overrun with anxiety, and just thinking about the disease makes them feel hopeless and without strength. They often abandon the treatment completely.

Patient 28, Dropout

I: So after that you didn't attend no more [to the health control sessions].

P: (smiling) No, I didn't go anymore, to tell you the truth. Then I came here.

I: And why did you decide to...

P: Fear. I didn't want anything, I wanted to die, I wanted... [...]. I had already failed the other doctor, I couldn't finish the diet, it was so hard! When they told me I had HT my legs trembled, I almost fell. I didn't want to go outside, I was afraid I would go out and would fall and no one would pick me up in the street.

Why did this have to happen to me? I didn't want anything, just close my eyes and sleep, because it's not easy.

# 3.3.3.3. How patients resolve their ambivalence

So far, only the main *anti adherence* voices have been presented. However, almost every patient revealed conjoint presence of both *anti* and *pro* adherence voices. When only *pro* or *anti* adherence voices were present (2 cases), there was no interaction, so those scenarios were called a *monologue*. When both kind of voices were present (49 patients), two main strategies for resolving ambivalence were observed: *Integration* & *Domination*. *Integration* was classified when patients acknowledged and accepted both voices, and was further divided between \*win-win \*and *compromise* (following the denominations of the Harvard Negotiation Model). *Domination* was when one voice tried to subject the other, and was divided between *Pro domination*, *Anti domination* & *domination* & *rebellion* (see table 2).

Table 2: Integration strategies are associated with higher and/or more stable patient adherence\*

Adherence	Pro	Win-	Compromise	Pro	Anti	Domination	Anti
	Monologue	Win		domination	Domination	& Rebellion	Monologue
High	1	4	9 (variant)	3 (typical)		1 (rare)	
	(general)	(typical)	,	(31 )		,	
Good		2	9 (variant)	1 (rare)	9 (variant)	2 (rare)	
Enough		(variant)					
Insufficient			7 (variant)	1 (rare)	9 (variant)	6 (variant)	
Dropout					2 (rare)	2 (rare)	1
Total	1	6	25	5	20	11	1

<sup>\*</sup> Each patient can use more than one strategy for resolving ambivalence, for example if he uses one for the diet behaviour and other for taking medication.

# 3.3.3.1. Monologue.

In the *Pro Monologue*, there are only *pro adherence* voices detectable in the interview, so there is no ambivalence or conflict. This happens in only one patient, who shows high adherence and says that "adhering is something good I do for myself, because I take care of myself".

In the *Anti Monologu*e, there are only *anti adherence* voices detectable in the interview, so there is no ambivalence either. It can be said that the patient is on the pre-contemplation stage. This happens in only one patient, who shows complete dropout and expresses that "hypertension runs in the family, I can't do anything about it, and besides, every time I go to the doctor I come home worse afterwards".

## 3.3.3.2. Integration.

In the *Win-win* integration, both voices can be accommodated and their goals accomplished, so both are "satisfied" and conflict is therefore resolved. This strategy is stable in time and is associated with high adherence, but it's only present on 12% of the sample.

For example, one patient was very afraid of having a stroke and losing autonomy (pro adherence voice), but at the same time he hated being too rigid and giving up control to the medical staff (anti adherence voices). So, he decided to stick to a diet with a medium term perspective, leaving room for occasional exceptions. Also, to go to the doctor but just to check if he was doing well with his strategy, using the professional as a health consultant, and not giving up control to him. This solution was successful for the patient, who expressed "I'm going to try like this, if it works I do as I say, if it doesn't I'll do as the doctor says".

In the *Compromise* integration, there is no option available to satisfy entirely both anti & pro adherence voices. So, the patient arrives at a compromise solution, in which both voices are heard and both have to yield. This solution is also stable in time, and is associated with good enough adherence, being observed in 49% of patients.

For example, a patient wants to have good health to share with her family and preserve her independency (pro adherence voices), but also doesn't like to do more exercise because it takes away time from her professional activities, and she has her HT compensated (anti adherence voices). So, instead of doing exercise three times a week, she does it only once, reaching a point of equilibrium in which protest from both voices are diminished. She says, "if I take

more care of myself and use my time going to the gym instead of doing what I do now, I would say I could live longer, but frustrated".

#### 3.3.3.3. Domination.

In the *Pro domination* strategy, the patient has very strong motivations to adhere, mainly because he's very frightened of what could happen to him. He has some *anti adherence* voices remaining, but those can't be expressed because he "must" adhere 100%. So, those *anti* voices are subjugated and the *pro* voices dominate. This strategy in the short term makes the patient adhere highly but it's not sustainable. Patients who used this strategy before the interview reported that after a while the fear decreased, they "relaxed" and adhered less, blaming themselves for that. So, this strategy is not stable, and is associated with high adherence only in the short term, being observed in 5 patients.

For example, one patient recently had a stroke and now is in partial recovery. He vows to adhere 100% to everything the medical staff says, because he's extremely afraid of another stroke (pro adherence voice). At the same time, he hates feeling controlled and leading a joyless life based only on healthy food (anti adherence voice). Faced with this ambivalence, and because his fear is so intense, he oppresses his anti voices, stating that "regrettably, now I have to abide, I have to forget of the tasty stuff".

In *Anti domination*, the patient has *pro adherence voices*, but even though he wants to adhere more, he feels that he *can't*. So, he lowers his adherence, but the pro voices are left dissatisfied and keep on complaining and blaming him for not doing what he should do. This is an unstable solution, because as those pro voices remain present, the patient will probably make another failed attempt in the future to adhere more. This strategy is more associated with insufficient adherence and was observed in 20 cases.

For example, a patient wants to adhere to the diet because he wants to be able to continue taking care of his children (pro adherence voice), but he uses food to regulate his work stress, so adhering to the diet implies increasing his anxiety (anti adherence voice). Faced with this ambivalence, he eats more than he

wants to, but blames himself, saying "I don't know why I don't have the willpower to do it".

Finally, in *Domination & Rebellion*, there is a struggle between *pro & anti* voices. The patient wants to subject her *anti* voices, but they are not easily pushed away and keep appearing in dysfunctional ways, or there is an alternation between *pro* and *anti* voices that can be seen even during the interview. Both voices fight for supremacy, and when the patient is in one, he sees the other as incomprehensible and malicious. There is no dialogue between the opposing voices and the person is in obvious inner tension. In this strategy, none of the voices is satisfied, and this oscillation (similar to the mutual in-feeding pattern described by Valsiner) is tense but stable in the long term. It was observed in 11 cases, associated with insufficient adherence.

For example, a patient wants to adhere 100% to the diet and exercise because she wants to be a good example to her children and a good patient for her doctor (pro adherence voices). At the same time, she feels weak and sick if she's taking care of her food intake and needs medication for life, and hates it when her children are supervising her meals (anti adherence voices). Faced with this ambivalence, she tries hard to adhere, but sometimes she is tempted to have a soft drink, and is when she yields she feels that all her effort went to waste. Other times, she strives to get to 100% adherence but she can't help herself and buys a cocacola hidden from her family so she's not scolded. She says "then I bring a bottle and I drink half of it, and then I look at it and say 'Oh my God, why did I do that at 3, 4 am?'".

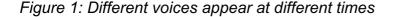
#### 3.4. Discussion

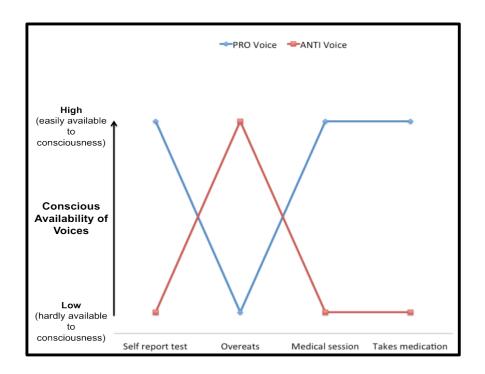
In this paper, it was argued that most people that need to make lifestyle changes face some degree of ambivalence between *pro* and *anti* treatment voices. Also, that those voices can be "heard" in different moments in time (even in the same interview), and sometimes they don't seem to acknowledge each other, evidencing lack of communication within the self. Furthermore, it was claimed that some data recollection methods allow the *anti* treatment voices to appear, while others don't, and that this is essential for adherence research and intervention. Patients' main *anti* adherence voices were explored, showing that resistant behaviour aims to preserve important values such as: self esteem, autonomy, affiliation, wellbeing, freedom and health (or just thinking adhering more is not worth the extra effort). Finally, different strategies for working through inner ambivalence towards adherence were described: *integration* strategies allow both opposed voices to express themselves and be heard, and were associated with higher and more stable adherence. On the contrary, *domination* strategies aim to reject or dismiss one of the voices, and were associated to poorer or less stable adherence.

The notion that the symptom or problematic behaviour has an adaptive function can remind the reader of concepts such as function of the symptom, primary and secondary gain, psychodynamic conflict, repetition compulsion, resistance as a selfprotection strategy, among other denominations (Frankel & Levitt, 2006; Killingmo, 1989; Palazzoli, Boscolo, & Cecchin, 1985). Accordingly, the study began with the belief that the symptom (in this case, the hypertension and associated health risks) had some important value for patients. Surprisingly, only in 4 cases (8%) there were traces of a positive value associated with having hypertension or uncontrolled blood pressure. In all other cases, when there was a positive value associated with non adherence, it wasn't related to the symptom, but to the things that needed to be done in order to alleviate the symptom. So it wasn't that people wanted to be ill (even for some self or system-protective reason), it was that what they needed to do in order to be healthier had other important costs. This is an important distinction, because the function of the symptom metaphor, although sometimes precise, has the risk of encouraging self blame, suggesting that some people "want to get sick", "like suffering", or "choose to sacrifice themselves for the family".

Regarding strategies to improve patient adherence, they usually focus on giving support, removing external barriers (e.g. complexity of dosage) and motivating the patient for compliance (Haynes et al., 2005; van Dulmen et al., 2007; Willey, 1999). With the notable exception of motivational interviewing techniques, all other intervention methods neglect or dismiss anti change voices, and like was said earlier, MI has a more rational understanding of the cons of change, thereby dismissing more implicit and not so easily conscious anti change voices. All of this means that most interventions, by focussing only on strengthening pro adherence motivations, risk promoting *dominance* strategies for resolving ambivalence, which in this sample were associated with poorer and less stable adherence. Furthermore, state of the art intervention programs make it very difficult for *anti adherence* motivations to appear and be heard, establishing a context of social desirability in which the patient fears scolding and self-blame for not behaving in the right way and lacking willpower or inner strength to adhere more.

These findings suggest that main problem is that the medical model encourages dialogue only with the *pro treatment* voice. This is the one that appears in the medical control session, and the one that is accessed using the self-report methods commonly used (see figure 1). When the patient talks to the medical staff, multiple contextual cues trigger the appearance of the *pro treatment* voice, hiding the *anti* voice into the background. A vicious circle then probably ensues: (1) the patient has little access to his anti adherence voices; (2) if the practitioner doesn't ask him about his non adherence, they remain hidden, but if he asks him about his reasons for non adherence, the patient has no access to his *anti* voice and thus (3) resorts to excuses and rationalisations; (4) this reinforces the practitioner's idea that there are no valid reasons for non adherence, making him dismiss them or making him angry at the "irrational" or "resistant" patient; (5) if the patient perceives criticism or disapproval from the practitioner, he'll be less prone to openly discuss non adherence in the future.





For adherence to be stable, its goals need to be established considering all the voices that command the patient's behaviour (McEvoy & Nathan, 2007). If the anti voices are neglected, there is great risk of poorer, less stable adherence. So, treatment goals should not be "100% adherence for everyone", because that's not realistic and appropriate to the experience of most patients. In this study, almost every patient with stable adherence reached a point of equilibrium, where they could adhere more, but that would have meant going against other personal values involved. So, they adhered until more adherence meant worse global outcome. Coherently, these findings suggest that in cases of ambivalence towards treatment and adherence, integration strategies should be encouraged. Just as has been seen in psychotherapy, promoting dialogue and accommodation between these conflicting voices helps ensure lasting change (W. Stiles, 2001).

Finally, adherence is a complex ethical issue. In almost every patient, there were more values at stake than just higher or lower blood pressure. For the practitioner or the health system it's easier, because they only measure and care if the patient attends the medical control session, and if he's got his HT under control. However, for most patients it's not that simple. What should they do when they have to balance higher blood pressure with other important values such as freedom, self-worth, and

even iatrogenic effects on other health variables? Should treatment goals only consider blood pressure, neglecting the other values at stake? Maybe the optimal treatment plan for some patients should not be 100% adherence. Maybe some patients are on the whole, better off reaching a compromise between these opposing voices. Finally, perhaps it's not healthy or ecologic to continue trying to dominate and win an internal battle against "resistant" forces, because if we use the war metaphor, whoever voice wins, we lose.

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# Appendix 1: Instructions for interviewers oriented to explore anti adherence positions

- 1. Looking at the adherence scores, identify elements of the treatment in which the patient doesn't adhere as he wishes to, or feels he should adhere more.
- 2. For each of these elements (e.g. Medication intake), identify the specific contexts in which the patient does not adhere (when, where).
- 3. Identify, for each context, what would be the "desired" adherent behaviour ("X"), and also what is the "real" non adherent behaviour ("Z").
- 4. For each context, coach the patient to experientially evoke that situation, and then ask (it's not necessary to ask all these questions, they are different alternatives):
- 5. In that context, what would happen if, instead of doing "Z", you do "X"?
- 6. Could there be a negative consequence of doing "X"?
- 7. What do you want to achieve by doing "Z"?
- 8. Use the *completing sentences* technique: Situate the patient in the non adherence context, and ask him to write down or speak up several times this sentence: "I'm in [the non adherent context], if I do [X], then...".
- 9. Ask the patient to think of someone who, in that context, would behave like "X". How would that person be? Does he know anyone like that?
- 10. Afterwards, ask about the consequences for the patient and family, of achieving the health goal.

# Appendix 2: Self-report short questionnaire (interviewer-administered)

**Instructions for interviewer**: First, specify the patient's goal regarding HTA and treatment adherence. Then, read the patient the following statements (substituting "the goal" for his particular goal), asking him to give a number between 1 and 5 for each statement, according to how strongly you agree or disagree. "1" is for complete disagreement, and "5" for complete agreement:

- The goal is desirable and worth the effort.
- It's possible to reach the goal.
- What I need to do to reach the goal (medication, diet, etc.) is appropriate and does me more good than harm.
- I have the necessary skills and resources to reach the goal.
- It's up to me to achieve the goal.
- Achieving my goal and my wellbeing in general, are a priority for me.

#### Conclusion

In the following pages, a synthesis of the main findings of this dissertation will be presented, organised according to the specific objectives stated before:

- 1. Patients' personality.
- 2. Interactional patterns between patients and caregivers.
- 3. Patients' anti and pro adherence positions or voices (motivational conflict).
- 4. Patients' experience of the treatment process over time.

Each factor will be presented regarding its influence or relationship with patients' adherence. Then, a comprehensive theoretical model will be presented, in order to understand how these factors, taken together, relate and explain patients' adherence to their medical treatment.

## Patients' personality

The main finding was that two major prototypical patients could be identified, according to their preference towards a more active or passive decision-making role in the medical treatment. They were named *keeping control* and *giving up control* positions. It's important to note that these positions are somewhat dynamic. For example, a patient can show a keeping control stance towards his physician, and a giving up control position towards his wife. Also, in some cases (7 out of 51) the patient showed both positions in the interview.

### **Keeping Control Position**

Patients who exhibit a keeping control position want to adhere "their own way", challenging the caregivers' decisions and preferring to arrive at their own conclusions regarding their treatment. They tend to see themselves as strong and autonomous, not liking to depend on others or feeling controlled. They often have a hard time accepting the restrictions imposed by the chronic illness' treatment. They have self-efficacy on their own coping abilities, so they fulfil the treatment indications when these are coherent with their own motivations and they agree that they are worth following. An expression representative of them would be: *I don't need anyone to tell me what I can or can't do*.

## Giving Up Control Position

They prefer to adhere following the caregiver's indications "to the letter", trusting his decision-making criteria instead of relying on their own choices regarding the medical treatment. For them it's not difficult to ask for help, and they like to be taken care of by others. Also, for them it's not difficult to accept the limitations and restrictions imposed by the illness and its treatment. They sometimes lack self-efficacy about their coping abilities and can rely on others to guide and remind them in order to take action. A characteristic expression would be: *I can't do this on my own, I need help and guidance*.

# How each position adheres

There is no clear difference between their overall adherence level (see table 2). However, the patients who keep control, when they face difficulties with the treatment, are more likely to drop out of the medical control sessions and continue with a partial adherence, on their own. On the other hand, patients who give up control tend to continue attending the medical control sessions, and when they face difficulties, they abandon aspects of the treatment. If they drop out of the control sessions, it's likely that they abandon the treatment completely.

Table 2: Number of patients that show different levels of adherence, according to their position towards treatment decision-making

Adherence Level	Keep Control	Give up control	Mixed position	Total
Optimal	7	7	1	15
Sufficient	10	3	2	15
Insufficient	8	5	4	17
Total dropout	2	2	0	4

Health control	Keep control	Give up control	Mixed position	Total
attendance				
Attends	16	14	5	35
Dropped out	11	3	2	16

# Factors influencing their adherence

Two factors that interact with the patients' prototypes and their overall adherence were observed. In patients who keep control, if they don't validate their own needs and limitations regarding the treatment and illness, they are more likely to have poor

adherence. This relationship is not clear among patients who give up control, because all of them tend to accept their limitations and needs.

A final factor was perceived social support. In patients who give up control, when they perceive lower social support, they tend to have poorer adherence. For patients who keep control, social support has no effect on their adherence, because they believe that they can handle their difficulties alone.

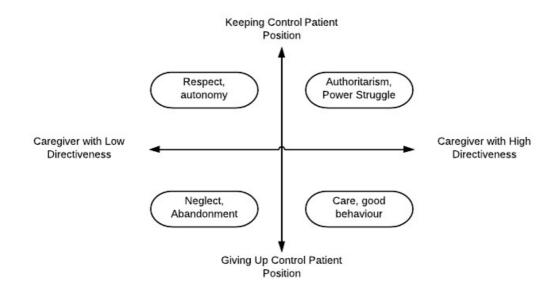
## Interactional patterns between patients and caregivers

The main finding was that the same caregiver's intervention can generate a positive effect on one kind of patient, and a negative effect on another. Also, the patients who keep and give up control tend to have different types of interactions with their caregivers. This section ends with emergent findings regarding how patients' implicit perceptions of the medical staff as authority figures influence their interaction with them.

## Interactional fit between patient and caregiver

Supporting previous research ((Christensen, 2000)), an interaction was observed between caregivers' directiveness and patients' preferred level of active participation (see in figure 1). Patients who keep control don't like to relate to caregivers in a hierarchical way. They adhere better when the medical team is non-directive and gives them freedom to choose; if the caregiver is too directive, a power struggle is in risk of happening, ending with dropout and the patient continuing treatment on his own. On the contrary, patients who give up control position the caregiver in a hierarchically superior place, adhering better when they are supported, guided and taken care of. If the medical team is too non directive, the patient can perceive that as indifference, and drop out or half-heartedly continue.

Figure 1: Interaction between patient and caregiver style

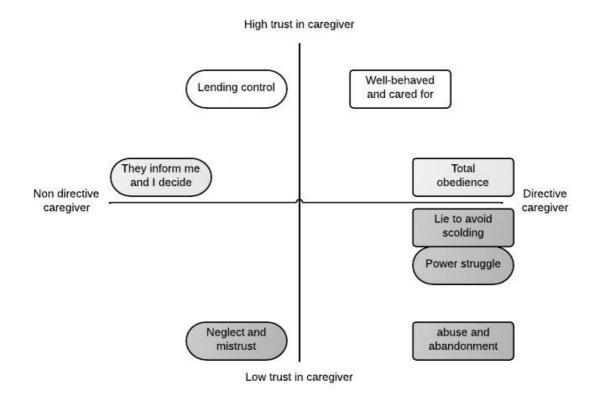


#### Different patients show different interaction patterns with caregivers

Analysis of the different interactional patterns showed that some interactions were more associated with higher adherence than others, as shown in figure 2. When patients who keep control have good adherence, they voluntarily and conditionally *lend control* to the caregivers. In cases of mixed adherence they engage the medical staff in a way called *They inform me and I decide*; but if the caregiver shows high directiveness, there can be a *power struggle*, associated with high risk of dropout. Finally, in poorer adherence cases, patients tend to feel *neglect and mistrust*, dropout and adhere on their own.

In the case of patients who give up control, when they have higher adherence, they tend to feel *well-behaved and cared for*. In cases of high but not sustainable on the long term adherence, they show *total obedience* to the will and indications of the medical staff. In cases of poor but sustainable adherence, they *lie to avoid being scolded*. Finally, in dropout cases, they *abandon to avoid further abuse* from the medical staff.

Figure 2: Different patient-caregiver interactions



## Patients' implicit perceptions of caregivers as authority figures

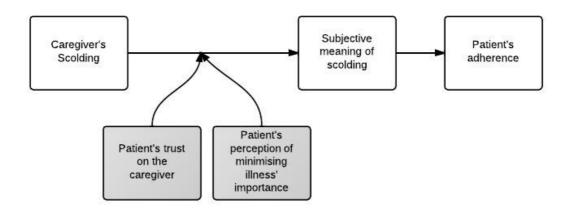
One important emergent finding was that in cases of poor adherence, there is a relational pattern in which one position (internalised, or personified on the caregiver) demands and criticises, and the other position rebels and refuses to comply (the patient, or another internalised part). Poorer adherence cases felt that they had no choice but to comply, and any dissent would face relentless persecution. This was contrary to the researcher's initial belief that lower adherence cases would show lower self-criticism or perfectionism. On the other hand, higher adherence cases didn't show this "top dog-under dog" (Perls, 1976) dynamic. These patients, despite claiming that they could adhere more and have better health, are satisfied with their efforts and accept their limitations. Also, when they feel that their caregiver is demanding from them more that they can do, allow themselves some dissent.

A related emergent phenomenon was called the *Mischievous Smile*, shown when the patient laughs or smiles while talking about or showing non adherent behaviour. This

non verbal sign was similar to Berne's "Gallows transaction" (Eric Berne, 1996), and was interpreted as evidence of an internalised critical parent voice, towards which the patient reacts with either defiance or asking clemency. As expected, the *mischievous smile* was associated with poorer adherence cases.

Finally, cases in which the patient reported having been scolded by someone in the medical staff were examined. Surprisingly to the researchers, some of those events were perceived positively, while others had a negative impact. Positive impact was associated with the patient minimising the importance of the illness and his adherence, plus high trust in the caregiver. Depending on the presence of these factors, patients perceived the scolding as a sign of unjustified and unacceptable authoritarianism, or a sign of caring and guidance (see figure 3). Thus, again it was found that, to predict how the patient would react to the caregiver's intervention, it was critical to know if he felt trust or mistrust, and if he implicitly regarded the professional as a critical or nurturing authority.

Figure 3: Trust and perception of minimising risks as requisites for scolding to have a positive effect



#### Patients' anti and pro adherence positions or voices (motivational conflict)

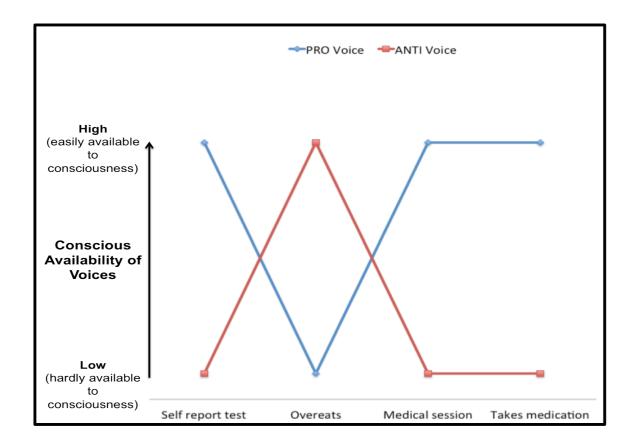
Regarding patients' ambivalence or conflict towards adhering, the first discovery was the critical importance of the interview method to learn the implicit anti treatment voices. Another finding was that almost all patients had powerful explicit or implicit motivations for non-adherence. Finally, patients had different strategies for dealing with their ambivalence.

### How to explore patients' anti adherence voices

The first finding was that patients show both *pro* and *anti* adherence voices or positions, but that often these positions within the self don't communicate between them, and only one is consciously available at any given time. This meant that a patient could explain in understandable terms why it made no sense for her to adhere more, and minutes later declare that she didn't know why she couldn't adhere more. This was regarded as a sign that sometimes the *anti* treatment voice is more salient or consciously aware, and other times it's implicit, hidden or not consciously available. Figure 4 shows an example of this, arguing that when patients have behaviours coherent with their *pro* voices like adhering, answering self report questionnaires and going to the health control session, they probably have only their *pro* adherence voice consciously available. On the other hand, when patients don't adhere, they probably have more conscious access to their *anti* adherence voices.

Also, it was noticed that when the interviewer asked the patients about their anti adherence voices in a straightforward manner, often they answered solely with their pro adherence voice, so their non adherent behaviour remained a mystery. On the contrary, when specific interview methods were used, adapted psychotherapeutic interview techniques (Ecker & Hulley, 1996), patients could access their anti adherence voices, and the interviewers could empathically understand their behaviour as coherent with their subjective emotional schemas and constructs. This method is explained in detail in the paper focused on this topic, and the curious reader can also study sample interview questions in appendix 4b.

Figure 4: Different voices appear at different times



#### What motivates patients to resist treatment adherence?

50 of the 51 patients in our sample showed presence of one or more anti treatment voices. Analysing their content, we observed that those voices represented important values: (1) For around half the sample, non adhering meant protecting their self worth, because they associate having hypertension and adhering to treatment to being hypochondriac, not normal or weak. (2) Others don't adhere in order to regulate their anxiety, because they use food for emotional coping. (3) Many don't adhere to protect their wellbeing and enjoying life, instead of being overly stressed and having to control their desires all the time. (4) Some patients don't comply when adhering would mean setting themselves apart from significant others, or prefer to sacrifice their health in order to avoid disturbing their family (for example, making salt-less food). (5) Roughly half the patients don't adhere in order to preserve their freedom and autonomy. (6) Also about half of them don't adhere because they fear iatrogenic effects from the treatment or directly via caregiver mistreatment. (7) Finally, many simply lack motivation to adhere more, either because they think it's not necessary to make the effort, or (in a minority of cases) because they feel that the treatment itself is a burden too heavy for them to carry.

#### Different strategies for dealing with ambivalence

The final (and also emergent) finding on this topic was that different patients used divergent strategies to deal with this ambivalence. In only two cases there are no traces of ambivalence, so these situations were denominated *Pro monologue* or *Anti monologue*, according to the sole kind of voice present. In the remaining patients, both kinds of voices were present, and two strategies for coping with ambivalence were defined: *Integration* and *Domination*.

**Integration** strategies allow both opposed voices to express themselves and be heard, and were associated with higher and more stable adherence. In the *Win-win* integration, both voices can be accommodated and their aims fulfilled, so conflict is resolved. In the *Compromise* integration, it's impossible to satisfy completely both conflicting goals, so the patient arrives at a compromise solution which allows stable "good enough" adherence.

On the other hand, **Domination** strategies aim to reject or dismiss one of the voices, and are associated to poorer or less stable adherence. In the *Pro domination* strategy, the patient has strong motivations to adhere (mainly fear associated), so he doesn't allow his *anti* adherence voices to express themselves, because he "must" adhere 100%. This is associated with high, but short lived, adherence. In the *Anti domination* situation, the patient wants to adhere more, but feels he can't, so he lowers his adherence but keeps complaining and blaming himself for not adhering more. Finally, when there is *Domination and rebellion*, there is a continuous struggle between *pro* and *anti* voices. The patient wants to subjugate her anti voices, but they are not easily pushed away and keep appearing in dysfunctional ways, or there is a power struggle between pro and anti voices that produce visible inner tension and oscillating adherence.

Finally, these different implicit or explicit strategies are associated with patients' adherence (see table 3).

Table 3: Integration strategies are associated with higher and/or more stable patient adherence

Adherence	Pro Monologu	Win-Win	Compromise	Pro domination	Anti Domination	Domination & Rebellion	Anti Monologue
High	1	4	9	3		1	
	(general)	(typical)	(variant)	(typical)		(rare)	
Good		2	9	1	9	2 (	
Enough		(variant)	(variant)	(rare)	(variant)	rare)	
Insufficient			7	1	9	6	
			(variant)	(rare)	(variant)	(variant)	
Dropout					2	2	1
					(rare)	(rare)	(general)
Total	1	6	25	5	20	11	1

#### Patients' experience of the treatment process over time.

Exploring patients' experience of their illness and treatment process, it was noticed that they reported very different initial reactions when they were diagnosed with their

hypertension. Also, there were different turning points in the treatment process, some of them helping them adhere more, while others triggered lower adherence. Furthermore, two new prototypical patients were defined, according to their attitude towards the future of their treatment and illness.

### Different initial reactions to the HT diagnosis

Four different initial reactions to the Hypertension diagnosis were observed:

- 1) Immediate adherence because the patient is already prepared: In this scenario, the patient is already prepared to adhere, probably because she has a family history of Hypertension, or because she already made the necessary changes in her lifestyle, so adhering doesn't require a big effort. These patients show little emotional reaction and appear to have little conflict about the diagnosis.
- 2) *Immediate adherence motivated by fear*: Alternatively, the patient is very afraid and starts adhering optimally, motivated by this fear about the terrible consequences of the disease.
- 3) *Minimising and denial*: These patients react initially downplaying the importance of the illness. Often they don't like to take medication or dislike going to the doctor because they prefer to deal with their illness themselves.
- 4) Shock and collapse: This reaction appears when the patient is very afraid about the consequences of the illness and the treatment. The patient is in shock, not being able to cope with the diagnosis, feeling paralysed, blaming himself or god for his misfortune.

#### Turning points in the treatment process

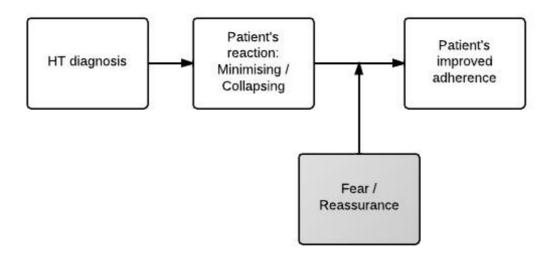
Analysing what happened to these patients after their initial reaction (from their own accounts in the episodic parts of the interview), we observed different developments.

- 1) Patients who were already prepared to adhere reported a stable adherence pattern. In this regard, caregivers only need to help them continue their adherent behaviour.
- 2) Patients who adhered immediately, motivated by fear, reported that after a while, fear subsided and they "relaxed" and their initial high adherence took a drop.

- 3) Patients who started minimising and in denial needed something to frighten them in order to adhere more. For example, seeing a someone close to them have a stroke, or hearing from friends that the illness has severe consequences if neglected. In this situation, caregivers help giving detailed information, or scolding but only if the requisite criteria (mentioned before) are met.
- 4) Patients who reacted initially with shock and collapse, contrary to the minimising patients, needed something to empower them and make them feel that the danger was not so big, or they had the strength to cope with the treatment. In this situation, caregivers need to focus on building rapport, trust and reducing fear, so giving information and scolding would be counter-productive.

Here we show which triggers foster adherence in patients who react minimising or in collapsing (see figure 5).

Figure 5: Minimisers need to be frightened, while those in shock need reassurance



#### Different attitudes towards the future

Finally, it was noticed that in some patients held a specially pronounced attitude towards the future and their abilities to cope with the illness and treatment. They were called *empowered* and *hopeless* attitudes.

Patients with an *empowered attitude* associate adhering to the treatment with self care and self appreciation. Adherence is linked with positive feelings, because they feel that formerly they didn't like themselves and didn't take care of themselves. They report that previously they went through depression or just tended to place more importance in others' wellbeing, postponing their own needs. Also, they feel that in the past they couldn't cope with treatment, but now they can, so again adhering is associated with feelings of strength and self-worth. They trust the medical staff, feeling grateful for their help, and play an active role in the treatment process. They adhere optimally, only indulging in occasional exceptions to treatment. A characteristic expression of them would be *I do this for myself*.

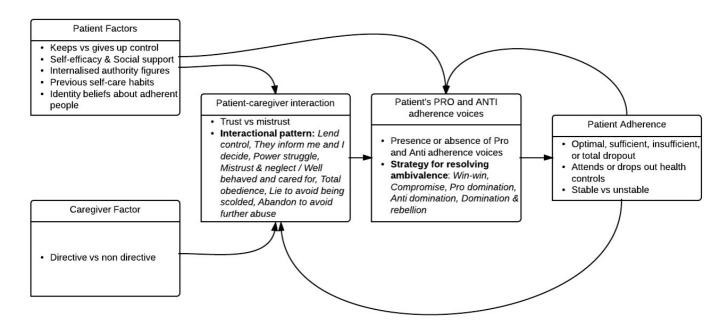
Patients with a *hopeless attitude* experience treatment as too heavy a burden for them to carry, and the illness as too terrible to cope. They feel as though they don't have the strength or will to try to adhere or deal with the problem. In general they are facing a very problematic life situation, or are in the middle of a depression, without the necessary energy to sustain the effort required to adhere. They don't trust the caregivers, viewing them as persecutory authorities. They adhere poorly or drop out completely, only improving their adherence if something happens that gives them hope or strength, or if they find a medical team that provides enough emotional support for them to trust them, and improve their self-efficacy. A characteristic expression could be *This is too much for me, it's not worth the effort because I just can't.* 

#### **General Discussion**

In this last section, the study's limitations are discussed, as well as its implications. Finally, are presented to integrate the different Regarding its limitations, this dissertation recognises three main ones. First, all methods to measure non-adherence have drawbacks and the chosen one (adherence interview) does not include any direct observation of patients actual behaviour, so there is a possibility that some results would be different if other method had been applied. Secondly, the population under study have relative cultural homogeneity, so the findings shouldn't be generalised to a different cultural group. Finally, there is a possible selection bias, as the people who accepted to participate have different characteristics than those who refused participation. The implications of the study were already presented in the three included papers. For example, the need for assessing patient and treatment characteristics and conducting interactional effects analyses ((Christensen, 2000)); the importance of applying appropriate interview techniques for exploring implicit anti adherence voices; the usefulness of classifying patients according to their position towards keeping or giving up control of the treatment; and the observation that the illness itself only had a "positive function" for less than 10% of the sample (for the vast majority, it was the non adhering behaviours that had a positive function, not "being ill"). Furthermore, this study hopes to contribute to state of the art theories on patient adherence and health behaviour, by illuminating factors neglected by these models, such as implicit emotional meanings, the multiplicity of the self, and the interactions between patient and the medical staff.

Before the final paragraphs, some words to help integrate the different topics included in this dissertation. Figure 6 shows the main elements covered and their interactions:

Figure 6: Main topics and their interactions



- Patient Factors: The patient can prefer to keep or give up control. Also, he can show high or low self-efficacy and social support; if neither of them is high, there is risk for hopelessness. The patient's internalised authority figures can be either critical & persecutory, or caring and nurturing. His self-care habits before getting the HT diagnosis can be similar or dissimilar from the ones recommended in the HT treatment; if they are similar, there is less chance for conflict. Finally, the patient has implicit beliefs of how adherent people are, and if they are positive, they are more likely to adhere.
- Caregiver Factor: The caregiver can show a more directive or non directive communicative style.
- Patient-Caregiver Interaction: There can be trust or mistrust. Also, one or more of the eight described interactional patterns can develop.
- Patient's Pro and Anti Adherence Voices: There can be a monologue if no ambivalence is shown, or one of the different strategies for resolving ambivalence, if it is present.
- Patient Adherence: Patients can show optimal, sufficient or insufficient adherence, or total dropout. Also, they can continue attending or not to the

health control sessions. Finally, adherence can be stable or sustainable, or unstable and short-lived.

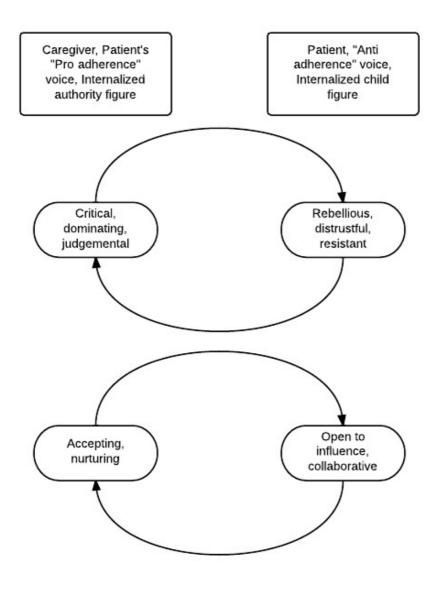
This figure also shows specific relations between these factors. Patient and Caregiver factors, when they interact, generate the different patient-caregiver interactions. Also, patient factors influence patients' *pro* and *anti* adherence voices. Patient-caregiver interaction is another variable that directly influences the presence or absence of *pro* and *anti* voices. Then, the presence of pro and anti voices, and the strategy for resolving ambivalence, determine patient's adherence, its level and whether it is short-lived or sustainable. Finally, patients' adherence influences back patients' pro and anti voices (for example, encouraging at positive results) and also influences patient-caregiver interaction (for example, inciting scolding or appreciation towards patients' good or bad behaviour).

#### Final Words

There is a final issue that need discussing, hoping it will help provide a coherent and global view of the different results. In the paper focused on interactional patterns, an argument was made on the importance of developing trust and how many poor adherence patients engage in a dysfunctional pattern of opposing, rebelling or defying (directly or indirectly) a critical or persecutory authority figure, personified in the caregiver. In the third paper, more focused on the dialogue between internal self positions, it was suggested that sustainable adherence can be achieved when patients don't use domination strategies to relate to themselves, but instead try integrating apparently dysfunctional *anti adherence* voices. In these final words, it is argued that these different conclusions are one and the same.

Whether it is an "external" or "internal" dialogue, all the findings point towards two very different types of interaction (see figure 7):

Figure 7: Critical vs Nurturing interaction



More importantly, the family, the medical system and most well-intentioned therapists engage the patient, implicitly, with a dominating-critical stance. Common sense belief is that, *obviously*, adhering is good and not adhering is bad. Even the patient himself, when thinking about his non adherence, often does it from a critical, judgemental and non-nurturing way. From a constructivist and dialogical perspective, every time we

say that non adhering is bad, irrational, unhealthy, incomprehensible or self-destructive, we are judging and rejecting the position of the patient that experiences non adherent behaviour as the most adaptive response (the *anti adherence voice*). Therefore, we are helping the *anti adherence* position become rebellious and resistant. As has been stated, domination-submission strategies can work for a while, but they are not sustainable over time, and later patients "relax" and stop adhering to the letter.

Of course, there are patients that don't have many problems adhering, mostly people who didn't need to make so many changes to their lifestyle, and those with an *empowered* attitude. But almost everyone has traces of anti adherence voices, or occasional difficulties in their adherent behaviour. In consequence, this dominating, demanding and judgemental view towards patients' adherence permits them little latitude for having a bad day in their treatment plan (Stanton, Revenson, & Tennen, 2007), and can make them feel so bad after perceived failure that they are less likely to continue striving towards their goal of better health (Neff, Hsieh, & Dejitterat, 2005).

Finally, this dissertation argues against domination or rejecting strategies (either inter or intrapersonal), and in favour of constructing more compassionate and accepting relationships with our patients and with ourselves. Both Intra and Interpersonally, domination generates power struggles and incites rebellion or subjugation. Hopefully, this dissertation can help caregivers empathise with their resistant patients, and resistant patients empathise with themselves.

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## **Appendices**

## **Appendix 1: Caregiver Interview Guide (Stage 1)**

- Explanations and attributions for patients' adherence.
- Distinctions regarding patients' adherence patterns.
- Reactions, attitudes and behaviour towards non adherent patients.
- Personal differences between adherent and non adherent patients.
- Interactional and medical team variables that differentiate between adherent and non adherent patients.

## Appendix 2: Observation guide for caregiver-patient health control (Stage 1)

- What communication patterns precede and come after patients' communication of non adherent behaviour?
- Is doctor-patient interaction symmetrical or complementary, horizontal or hierarchical?
- What does the doctor do to facilitate or improve patient's adherence?
- Do patients' and doctors' interpersonal patterns and roles change during the interaction? How is their evolution?
- How can doctor-patient interaction be characterised in terms of controlsubmission?

## **Appendix 3: Patient interview guide (Stage 1)**

- Patient's perception, experience and evaluation of the treatment.
- Patient's criteria to evaluate medical treatment.
- Patient's beliefs about the causes, consequences and treatment of their illness.
- Patient's perception, experience and evaluation of their own participation in the treatment.
- Patient's experience about their own adherence to medical treatment (differentiating medication, exercise, diet and other health-related behaviours).
- Patient's perception of changes in their motivation and active cooperation during treatment process.
- Patient's perception of the variables that facilitate and impair adherence.
- Patient's perception about the treatment's impact on their family and their participation in it.
- What are the easiest and most difficult aspects of adhering to treatment?
- · Contexts or situations that trigger adherent and non adherent behaviour.
- Patient's motivations for adhering, and associated personal values.
- Patient's motivations for not adhering, and associated personal values.
- What does the resistant behaviour do for the patient that is valued or needed in the patient's world?
- Patient's perception of the costs and benefits of adhering to medical treatment, not adhering, improving their medical condition, and not improving it.
- Patient's experience and evaluation of doctor communication and interaction during medical follow-up interviews.
- Similarities and differences between patients' initial expectations and their current perception of medical treatment.
- Patient's current expectations regarding the treatment and their illness.

#### **Appendix 4: Patient interview guide (Stage 2)**

## Evolution of the patient's participation in treatment

- Initial reactions to the diagnosis.
- Events that have triggered an improvement in patient adherence.
- Events that have triggered a decrease in patient adherence.

#### Health and self care

- Perception of current health: real, wished, expected.
- Historic self care habits and how he's dealt with health problems.
- · Perceived consequences of having HT.
- Experience of having the illness.
- Experience of the treatment.
- Attributions and causes of the illness.

#### Motivations to adhere

- Reasons for adhering or trying to reach the health goal.
- Perceived or expected difference between continuing to adhere like now, adhering "to the letter" (100% what the doctor indicated), and dropping out of treatment completely.

#### Personality and psychological resources

- Coping strategies.
- · Emotional regulation.
- Discipline, self-criticism.
- Strategies for motivating himself for adhering.
- Resources needed and used for adherence and self care.

#### Interaction with caregivers and internalised relational patterns

**Instructions**: Ask for 2–3 relational episodes in which there was some difficulty or impasse with medical team (if no impasse reported, a "usual" episode, and a conflictive one with other person).

- Self reliance or asking for help when in trouble.
- Locus of control.
- Strategies for resolving interpersonal conflict.
- Reaction when receiving indications and directives.
- Feeling appreciated or criticised by doctors.
- Meaning of going to the doctor, and of medicine in general.
- Impact of illness and treatment on family.
- Desired interaction with caregivers.

# Appendix 4b: Instructions for interviewers oriented to explore anti adherence positions (Stage 2)

- 1. Looking at the adherence scores, identify elements of the treatment in which the patient doesn't adhere as he wishes to, or feels he should adhere more.
- 2. For each of these elements (e.g. Medication intake), identify the specific contexts in which the patient does not adhere (when, where).
- 3. Identify, for each context, what would be the "desired" adherent behaviour ("X"), and also what is the "real" non adherent behaviour ("Z").
- 4. For each context, coach the patient to experientially evoke that situation, and then ask (it's not necessary to ask all these questions, they are different alternatives):
  - o In that context, what would happen if, instead of doing "Z", you do "X"?
  - Could there be a negative consequence of doing "X"?
  - What do you want to achieve by doing "Z"?
  - Use the completing sentences technique: Situate the patient in the non adherence context, and ask him to write down or speak up several times this sentence: "I'm in [the non adherent context], if I do [X], then...".
  - Ask the patient to think of someone who, in that context, would behave like "X". How would that person be? Does he know anyone like that?
- 5. Afterwards, ask about the consequences for the patient and family, of achieving the health goal.

## **Appendix 5: Adherence interview**

**Introduction**: "When you have an illness or go to the doctor for some problem, it's usual that you are given some indications about medication, diet, exercise, etc. Many times things happen that make us adjust those indications and change them, and in the end it's common that we follow the indications in a different way than how we talked about them with the doctor. We want to know about your experience, what did you talk initially with the medical staff and what have you done in your everyday life".

**Instructions for interviewer**: Build *rapport*. Ask with implicit forgiveness and no implicit value judgements. For example: "could you?", "what difficulties have you encountered?", "when was the last time you couldn't take the medication?". It's better to assume that the patient didn't do it, than force a confession. Never ask "did you do X?".

Complete the following table: First ask the patient about the specific instructions that the doctor indicated, for each treatment aspect. Then, complete the following table with the appropriate percentage. "100%" is for following doctor's indications "to the letter".

Table 4: Adherence interview (Appendix 5)

Aspects of treatment	Real % (according to patient)	Wished % (by the patient)	Expected % in the future (by the patient)
Health control attendance			
Medication			
Diet			
Exercise			
Alcohol, tobacco, etc.			
Others: Mealtimes, rest, sleep			

## Appendix 6: Self-report short questionnaire (interviewer-administered)

**Instructions for interviewer**: First, specify the patient's goal regarding HTA and treatment adherence. Then, read the patient the following statements (substituting "the goal" for his particular goal), asking him to give a number between 1 and 5 for each statement, according to how strongly he agrees or disagrees. "1" is for complete disagreement, and "5" for complete agreement:

- The goal is desirable and worth the effort.
- It's possible to reach the goal.
- What I need to do to reach the goal (medication, diet, etc.) is appropriate and does me more good than harm.
- I have the necessary skills and resources to reach the goal.
- It's up to me to achieve the goal.
- Achieving my goal, and my general wellbeing, are a priority for me.

#### **Appendix 7: Stage 1 Results**

From the analysis in the first stage, five hypothetical models were developed:

- 1. Patients can be classified in 4 scenarios: They were called "scenarios" because they represent different ways of experiencing and positioning towards the treatment and the illness, but are not rigid. 4 were distinguished:
  - Empowered: Reports neglecting himself before, and now experiences
    the treatment as a way of taking care of himself and valuing himself. A
    characteristic phrase would be: "I do it for myself, because I take care
    of myself".
  - Hopeless: Feels that having the illness and following the treatment is too difficult, too heavy a burden for him to carry. A representative expression would be: "This is too much for me, there is no point in making the effort, I can not cope with it".
  - Strong-independent: A crucial value in the self-concept of these patients is self-reliance. They like to face difficulties alone, preferring to help others than ask for help. They don't like feeling controlled or needing others. Also, they have trouble recognising their own limitations. A characteristic expression would be: "I don't need anyone to tell me what I can or cannot do".
  - "Dependant": The patient receives gladly the help of others, experiencing it as sign of concern and care. He places the caregiver in an authority position, not assuming much of the responsibility for the success of the treatment. A representative expression might be "I can not do this alone, I need help and guidance".
- 2. Patients' adherence is related to these 4 "scenarios": The hopeless have insufficient adherence, or drop out of the treatment. The empowered have optimal or sufficient adherence. The dependant adhere optimally or sufficiently when they have enough social support (from personal networks and from caregivers). Finally, the strong-independent adhere if they are not in a power struggle with their caregivers, and if their motivations to adhere are coherent with their sense of self (and therefore assume self care and accepting limitations as something coherent with their identity).

- 3. Patients have different reactions to the HT diagnosis: The *strong-independent* react with initial minimisation. The *dependent* and the *hopeless* initially collapse. Finally, the *empowered* start adhering immediately.
- 4. **Different kind of events trigger improved adherence**: Those who minimise at first, will adhere more if there is a frightening event. Those who collapse initially, adhere more if there is an empowering event.
- 5. Different reactions to caregivers' interventions: If the caregiver shows high directiveness, the *strong-independent* react with reactance, the *dependent* try to behave like a "well-behaved child" (trying to adhere "to the letter") and the *hopeless* have a passive-aggressive reaction. If the caregiver shows low directiveness, the *strong-independent* try to adhere their own way, the *dependent* and *hopeless* externalise responsibility and drop out.

## **Appendix 8: Informed Consent**

I, \_\_\_\_\_\_\_, have been invited to participate in a study about the treatment of arterial hypertension, with the goal of exploring different factors that facilitate or hinder patients' adherence to the treatment. I understand my participation in the study will be recorded on audio and video. If I wish, I can ask for the camera to be turned off at any moment.

My specific contribution to the study can be an individual interview and allowing a health control session to be videotaped. Also, if I accept to participate, the researchers will know some information about my treatment (comorbidities, attendance to previous health control sessions).

I understand that I can decide to withdraw from the research at any time, and it will not affect the treatment I follow in this institution, or or future attentions I might need. Furthermore, in the future if I want my data to be removed from the study, I can freely ask for it.

Finally, I understand that all information recorded will be confidential and known only to the research team, without being transmitted to treating professionals, or any other parties at the medical institution.

I understand this consent form and accept to participate in the study.

Please check all that apply, if you agree to:

[] Participate in the individual interview.
] Allow observation of a health control session.
[] Allow these data to be used on a future study on the same topic, keeping complete
anonymity.
Date:

If you have questions regarding the study, you can contact Pablo Herrera Salinas (main researcher) at 3541242 or paherres@uc.cl. Also, you can contact the ethics committee of the Pontificia Universidad Católica de Chile, at 3545883 or comite.etica.psicologia@uc.cl.

## Erklärung gemäß § 8 Abs. 1 Buchst. b) und c) der Promotionsordnung der Fakultät für Verhaltens- und Empirische Kulturwissenschaften

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Erklärung gemäß § 8 Abs. 1 Buchst. b) der Promotionsordnung der Universität Heidelberg

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