Understanding Non-Adherence From the Inside: Hypertensive Patients’ Motivations for Adhering and Not Adhering

Pablo A. Herrera¹, Laura Moncada¹, and Denise Defey²

Abstract

Patients’ low adherence to medical treatment in chronic illnesses is one of the biggest public health problems. Numerous studies attend to the diverse factors associated with patient adherence. However, little research has been done to explore patients’ reasons for non-compliance from their own point of view. In this article, we aim to understand patient non-adherence using dialogical self-theory and qualitative research methods. We interviewed 51 hypertensive patients to explore their anti- and pro-adherence motivations. Results show that most patients adhere and non-adhere to different aspects of treatment programs (medication, exercise, diet) according to the way they construct meaning to those activities. Also, our findings support the notion that patients’ non-adherent behavior aims to preserve important values such as self-esteem, autonomy, affiliation, well-being, freedom, and health (or that more adherence is not worth the extra effort). We discuss the therapeutic relevance of empathically understanding patients’ worldview and implicit beliefs.

Keywords

adherence; health behavior; motivation; users’ experiences; behavior change; content analysis; south america

In this article, we aim to explore and understand hypertensive patients’ explicit and implicit motivations to adhere and not adhere to their medical treatment from their own perspective. Understanding their motivations to not adhere is relevant as the prevalence of chronic illnesses has been rising (e.g., in Western countries, hypertension [HT] has a 20% prevalence and is higher in older populations), and their treatment focuses on changing patients’ lifestyles and habits (Karakurt & Kaşikçi, 2012; World Health Organization, 2003). Even though treatments are usually effective, patient adherence is low, around 30% to 60% for medication and lower for diet and exercise (Dunbar-Jacob, Schlenk, & McCall, 2012; Martin, Williams, Haskard, & Dimatteo, 2005). There are different theoretical models to understand patients’ non-adherence, such as the social cognition theory, the health beliefs model, theory of planned behavior, the protection motivation model, and the common-sense or self-regulatory model (Bosworth, Oddone, & Weinberger, 2006; Christensen, 2004; Meyer, Leventhal, & Gutmann, 1985; Munro, Lewin, Swart, & Volmink, 2007; Ortiz & Ortiz, 2007). Researchers have conceptualized adherence 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, and visibility of symptoms (Meichenbaum & Turk, 1987; World Health Organization, 2003). Also, they have been able to adequately predict patients’ intentions to adhere (Bosworth et al., 2006; Christensen, 2004). However, these conscious intentions do not fully explain or predict future behavior changes (Christensen, 2004; Webb & Sheeran, 2006; Westra, 2011). Also, intervention programs to improve patients’ adherence are very complex, resource intensive, and have shown moderate results (Haynes, Yao, & Degani, 2005).

To contribute to adherence research, some methodological and theoretical limitations need to be addressed. Methodologically, traditional research mainly uses self-report questionnaires to assess patients’ conscious and
rational intentions, beliefs and attitudes toward the treatment and illness (Lehane & McCarthy, 2007; Lubaki, Mabuza, & Maleto, 2009; Marx et al., 2011; Pound et al., 2005), leaving more implicit or emotional schemas unattended (Smith & Greenberg, 2007). Theoretically, most models utilized to understand medical non-adherence regard it as a behavioral problem, something that must be fought against, caused by irrational biases and beliefs (Beutler, Moleiro, & Talebi, 2002; Levensky, 2006). Other theoretical frameworks, such as the stages of change model, study patients’ ambivalence toward the treatment, proclaiming that its presence at the beginning of the treatment is a strong predictor of patient drop-out (Brogan, Prochaska, & Prochaska, 1999; Prochaska, DiClemente, & Norcross, 1992). However, there are very few studies focused on exploring and describing patients’ motivations to adhere and not adhere (Pound et al., 2005).

In addition, except for the motivational interviewing technique, most intervention programs do not consider the importance of the anti-adherence motivations (Britt, Hudson, & Blampied, 2004). In summary, most research and intervention projects focus on empowering the more conscious pro-adherence motivations and beliefs, neglecting more implicit processes, such as the anti-adherence motives.

In our research, we address this problem from a constructivist and dialogical point of view, originating from psychotherapy research on resistance to change (Ecker & Hulley, 1996; Hermans, Kempen, & Van Loon, 1992). According to this theoretical framework, non-adherence or resistance is not a manifestation of irrational or destructive aspects of the personality but an expression of conflict between different internal motivations or voices. Some of these voices are coherent with the adherence behavior, while others promote non-adherence behavior of the patient. But according to this theoretical perspective, both pro- and anti-adherence voices express values and emotional experiences that need to be acknowledged, not dismissed or rejected.

To explore patients’ motivations for non-adherence, we conducted and analyzed interviews with 51 hypertensive patients. We used interview techniques adapted from psychotherapy research (see, for example, Ecker & Hulley, 1996) with the aim of exploring implicit constructs that are not easily available using standard self-report measures or qualitative interviews.

A better understanding of patients’ resistances and values could help change what is often a confrontational disposition toward non-adherent patients, by allowing caregivers to empathize with their needs and motivations. Furthermore, this could contribute toward personalizing adherence enhancing interventions, making them more appropriate to each specific patient and favoring their active collaboration (Creer, Holroyd, Glasgow, & Smith, 2004; Fisch, Weakland, & Segal, 1982; Pound et al., 2005).

Studies on Patients’ Motivations

Different theoretical models have been developed to understand what motivates a patient to adopt health behaviors. Most of them assume that the patient conducts a rational evaluation of the pros and cons of the proposed behavioral change. Among them, the original and most widely used is the health beliefs model (Bosworth et al., 2006; Cabrera, Tascón, & Lucumi, 2001; Christensen, 2004; Munro et al., 2007), developed to understand why people did not adopt preventive behaviors. It includes the following key elements: perceived threat of a disease (including perceived susceptibility and perceived severity of such a disease), perceived benefits of the health behavior, perceived barriers to that behavior (including time, monetary cost, stigma, side effects), and a cue to action.

More recent theoretical models have incorporated new elements that allow for a more complex understanding of patients’ health behavior: The theory of reasoned action emphasizes social norms; the theory of planned behavior includes patients’ perceived behavioral control; other researchers emphasize patients’ irrational health beliefs as distortions that hinder adherence; the protection motivation theory states that sometimes non-adherence is the product of patients’ maladaptive coping mechanisms (so it has a self-protection aim); the self-regulation model incorporates the patients’ continuous assessment of the effects of the coping behavior on the disease; and the information-motivation-behavioral skills model asserts that motivations and information are not enough to understand adherence as we must consider the patients’ behavioral skills as well (Bosworth et al., 2006; Christensen, 2004; Munro et al., 2007; Ortiz & Ortiz, 2007).

So, for these researchers, patients are motivated to adhere when they (a) perceive a high threat if they do not adhere, (b) perceive low costs of adherence, (c) regard the risk as controllable by them, (d) do not present cognitive distortions about the disease and treatment, (e) use healthy coping mechanisms, (f) present the required behavioral skills to engage in the expected health behavior, and (g) have positive feedback.

Other health scientists have focused on patients’ personal representations of the illness and their subjective assessment of their situation. Leventhal’s common-sense model has helped researchers and caregivers to focus on patient’s lay representations of the illness (Meyer et al., 1985; Munro et al., 2007; Quiles, Terol, & Marzo, 2009), and not on objective consequences and a purely rational...
analysis of costs and benefits. Leventhal proposes that it is necessary to explore individuals' subjective experience of the illness to understand the way in which they cope with and adapt to it. This process of creating representations and selecting coping mechanisms is influenced by an individual's personality and his or her cultural context (Munro et al., 2007). In addition, Janis and Mann's decisional balance theory (Di Noia & Prochaska, 2010; Janis & Mann, 1977; Prochaska et al., 1994) has highlighted that patients perceive different costs and benefits of both adherence and non-adherence. Motivational interviewing techniques use this model to explore these pros and cons with each patient, helping them tilt the balance toward adherence (Emmons & Rollnick, 2001; McEvoy & Nathan, 2007).

Fewer researchers in health psychology have focused their attention on what motivates patients' non-adherence. This is especially important, given that patients' non-adherence is often intentional (Lehane & McCarthy, 2007). Most researchers on the topic use qualitative data recollection methods (interviews, focus groups), and are interested in cultural factors and personal beliefs. Summarizing the findings of different studies on chronic illness and HT, patients give the following reasons for non-compliance: (a) concerns about the adverse effects of medication, (b) concerns about the stigma associated with some illnesses, (c) fear of dependence on treatment, (d) distrust toward medical doctors and institutions, and (e) the perception that their problems were not too severe (Lukschek, 2003; Pound et al., 2005; Unson et al., 2003; Viswanathan & Lambert, 2005).

How to Deal With Patients' Non-Adherence?

After summarizing studies and theoretical models to understand patients' motivations for adherence and non-adherence, it is necessary to describe different ways of responding to non-adherence. Most health psychology theoreticians regard patient non-adherence as a manifestation of irrational beliefs, cognitive biases, lack of information about the risks of not adhering, or underdeveloped behavioral and coping skills (Beutler et al., 2002; Bosworth et al., 2006; Christensen, 2004; Levensky, 2006; Meyer et al., 1985; Munro et al., 2007; Ortiz & Ortiz, 2007). Thus, their interventions focus on strengthening the patients' reasons for adhering and fighting the cognitive and practical barriers for adherence. Even motivational interviewing, from a non-directive stance, has the explicit aim of promoting the patients' motivation for adherence (empathetically exploring their reasons for not wanting to, but still with the purpose of motivating them to adhere). So, from these perspectives, patients' non-adherence or resistance is something that needs to be challenged and fought against.

However, recent developments originating from the study of psychotherapeutic change have proposed that patients' resistance is not a manifestation of irrational or destructive aspects of the personality but an expression of conflict between different internal parts, positions, modules, or voices (Dimaggio & Stiles, 2007; Hermans et al., 1992; Honos-Webb & Stiles, 1998; Kurzban, 2011; Lester, 2007; Rowan, 2010). From this perspective, we encounter ambivalence and resistant behavior when both pro- and anti-chance motivations or voices are present. What to do once this ambivalence is acknowledged? In general, these researchers state that exclusive dominance of one part of the self over all others is problematic. Therefore, an important therapeutic aim should be to help patients be aware and acknowledge parts of the self previously in the shadows, like the anti-treatment voices (Dimaggio & Stiles, 2007).

These researchers also assume the inner coherence of the self. This means that every activity of the mind, conscious and unconscious, is coherent with its current constructions of meaning (Ecker & Hulley, 1996). 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). So, non-adherent behavior would be coherent and adaptive to the patient, according to his present construction of meaning.

This perspective has been used in psychotherapy research (Ecker, Ticic, & Hulley, 2012; Rice, Neimeyer, & Taylor, 2011) and has recently been studied in health psychology topics, exploring subjective meaning and internal voices in teenage patients with chronic fatigue syndrome (Fuchs et al., 2013; van Geelen, 2010). The present article adopts the assumption that in dealing with non-adherent or resistant behavior, the first order of business is to understand how that behavior is coherent, adaptive, or valid for the patient, in a certain context or with a certain internal voice. As in psychotherapy, we assume that fighting the “resistant” or “anti-adherence” voice would generate more resistance, while acknowledging and accepting it could open up possibilities for cooperation and change (Cowan & Presbury, 2000; Ecker & Hulley, 1996; Engle & Arkowitz, 2008; Engle & Holiman, 2002).

Method

Research Design

The design of this study was non-experimental, cross-sectional, exploratory, descriptive, and comparative. Qualitative content analysis was used to explore patients’
experiences and subjective processes. Some aspects of grounded theory and consensual qualitative research were used for the sampling, data recollection, and analysis procedures (Glaser & Strauss, 1967; Hill et al., 2005).

Sample

We used theoretical sampling, gathering more data until the theoretical saturation criterion was met (Glaser & Strauss, 1967), for a total of 51 patients interviewed. 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 researcher’s personal networks.

- The inclusion criteria were as follows: arterial HT diagnosis, between 25 and 80 years of age, self-reliant (does not depend on others to make health and treatment decisions), voluntary participation for at least 1 month in a public or private HT medical treatment program (except for the participants in the “total dropout” adherence level), living in Santiago de Chile with Chilean nationality, and required to make lifestyle changes as part of the medical treatment.

- Exclusion criteria were as follows: cognitive impairment, psychiatric illness, current comorbidity with another acute illness.

For the selection of participants with different levels of adherence to the medical treatment, we needed to operationalize these levels. After a literature review and consulting with different health care professionals, we defined the following adherence levels:

1. Optimal: compensated arterial pressure (<140/90) in the last two medical check-ups. Furthermore, the patient is satisfied with his adherence to the different aspects of the treatment (diet, drugs, exercise, others), without the need or desire to adhere more.

2. Sufficient: compensated arterial pressure (100<140/60<90) in the last two medical check-ups. Patient adheres partially, not as much as he would like or think they need.

3. Insufficient: The same as the “sufficient” group, but their arterial pressure is not compensated (>140/90).

4. Total drop-out: They have not been to medical check-ups for at least 2 years. They adhere minimally, if at all. These participants are exempted from the inclusion criteria of participating in a HT treatment for at least a month, as they are not in any kind of treatment for their HT.

The final sample can be seen in Table 1:

Table 1. Composition of the Sample (Adherence and Health System).

<table>
<thead>
<tr>
<th>Adherence Level</th>
<th>Private Health</th>
<th>Public Health</th>
</tr>
</thead>
<tbody>
<tr>
<td>Optimal</td>
<td>7</td>
<td>8</td>
</tr>
<tr>
<td>Sufficient</td>
<td>7</td>
<td>8</td>
</tr>
<tr>
<td>Insufficient</td>
<td>9</td>
<td>8</td>
</tr>
<tr>
<td>Total drop-out</td>
<td>1</td>
<td>3</td>
</tr>
<tr>
<td>Total sample</td>
<td>24</td>
<td>27</td>
</tr>
</tbody>
</table>

Data Collection Instruments

We recollected all the data using in-depth interviews with hypertensive patients (see the appendix for the full interview guide). These explored in detail different episodes of patient–caregiver interaction (including physicians, nutritionists, and nurses), milestones in the patient’s history with his illness, his coping strategies, and utilized specific questions to explore implicit pro- and anti-treatment motivations and implicit schemas. Complementarily, all interviews gathered information about patient’s adherence to different aspects of the medical treatment, and their perception that they should or should not adhere more. The patient’s self-report was complemented with data from patient’s medical records (specifically, weight, blood pressure, and assistance to medical check-up sessions), when this information was available.

All interview sessions lasted between 40 and 120 minutes, with an average of about 75 minutes of duration (one session per participant), and were conducted in the interviewees’ homes or, if they so preferred, in the medical center where they received the medical check-ups. All interviews were videotaped and later transcribed. Only the interviewer and interviewee participated in the sessions. Using an iterative process, the interview guide was modified for new interviews, after the analysis of previous interviews (Beebe, 2001).

Data Analysis

For the data analysis, we followed the general guidelines of the grounded theory and consensual qualitative research (Hill et al., 2005; Strauss & Corbin, 2002): several judgments throughout the data analysis process to foster multiple perspectives; consensus to arrive at judgments about the meaning of the recollected data; one auditor to check the work of the primary research team; and cross-analyses of domains and core ideas. Also, we conducted all analyses using the transcripts from the interviews. We also used qualitative research software to help with the coding procedure (Atlas.ti 7).

The relational nature of the study goals required the comparison of data between sub-samples. To do so, we developed the following procedure:
1. Interview Level 1: We classified each patient according to his adherence level (optimal, sufficient, insufficient, and drop-out, as defined earlier).

2. Interview fragment Level 1: We analyzed every interview individually, selecting fragments (units of meaning, varying in length between one word and several sentences) in which the interviewee valued acknowledging the illness or following the treatment plan positively or negatively.

3. Interview fragment Level 2: In each interview, we coded every fragment according to these initial domains: anti-treatment voice (any expression that had, according to the patient, a negative association with adhering to treatment) or pro-treatment voice (any expression that had a positive association with adherence).

4. Interview fragment Level 3: In each interview, for each coded domain, we selected and edited a core idea, expressing what the patient had said in that fragment.

5. Global Level 1: After selecting a sub-sample of 15 interviews according to the maximum variation criteria (representing widely different experiences regarding their adherence), we analyzed and classified all coded fragments in emergent sub-domains. We then selected and labeled these sub-domains according to the personal values or positive aspects associated with each pro- and anti-voice. This step produced an initial list of pro- and anti-treatment voices.

6. Global Level 2: With this initial list of pro- and anti-treatment voices, we coded all the other interviews and analyzed each selected fragment, creating new codes as needed to capture the patients’ personal meanings. This continued until no new domains or core ideas emerged (theoretical saturation point), at which point we completed a list of eight anti- and nine pro-voices, which were representative of the whole sample (51 interviewees).

7. Interview Level 2: Going back to each individual interview, we classified every patient according to the presence or absence of the different pro- and anti-voices. This allowed us to describe associations between the presence of each individual voice and the patients’ adherence level.

Ethical Considerations

To preserve participants’ autonomy and confidentiality, we recorded all the information 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. The interviewers were all accredited psychotherapists with at least 5 years of professional experience and specific training for this kind of interview. The ethics committee of the Catholic Pontifical University of Chile approved the study.

In summary, our total sample size was 51 hypertensive patients, collecting the data using in-depth interviews of approximately 75 minutes each. From these interviews, we discovered nine pro-adherence voices and eight anti-adherence voices. Also, almost every patient presented both pro-adherence and anti-adherence voices.

Results

Almost every interviewed patient (96%) exhibited both anti- and pro-adherence voices. This means that they showed presence of one or more pro-adherence voices, and (in another moment of the same interview) one or more anti-adherence voices.

First, we will introduce the content of the patients’ main pro-treatment voices, followed by the content of patients’ main anti-treatment voices. We labeled each pro- and anti-treatment voice representing their subjectively perceived value.

Pro Adherence Voices

In the following paragraphs, we present patients’ main pro-adherence voices, according to the goals or motivations they associate with their adherence.

Nine pro-adherence voices emerged, which we classified in five broader categories. Table 2 presents them and their relationship with patient adherence.

Self-Worth (“I Do This for Myself, Because I Care for Myself Now”). For some of the HT patients in the sample (31%, \( n = 16 \)), adherence meant that they were taking care of themselves. They perceived it as a sign of self-care and appreciation. Thus, for them (when this voice is salient) adherence is associated with positive feelings.

This is especially relevant for a subgroup of patients (10% of the total sample) who reported that they had previously been depressed or just tended to place more importance on others’ well-being, postponing their own needs. Also, they felt that in the past they could not cope with treatment, but now they can, so adherence is associated with feelings of strength and self-worth. They adhere optimally, only indulging in occasional exceptions to treatment.

Well-being (“I Control My Hypertension Because I Want to Have Good Health”). Most patients (86%, \( n = 44 \)) experience adherence as being related to improving their well-being. Three specific voices emerged: noticing benefits,
fear of consequences, and being even better. However, although these patients are conscious of the positive consequences of adherence and negative consequences of non-adherence, only 59% of all patients who presented this pro-voice adhere in a sufficient or optimal manner.

Noticing benefits (“I continue my treatment because I have noticed how my blood pressure goes down and I feel healthier”). Half of the HT patients (53%) associate adherence with noticing health benefits such as feeling more active, having less pain, sleeping better, and a general sense of being healthier.

Fear of consequences (“I follow the doctor’s orders because I am terrified of what will happen to me if I do not”). The majority of the HT patients express fear of the consequences of non-adherence (65%). Some express a very specific fear (e.g., “I do not want what happened to my father to happen to me”), whereas others show a more abstract apprehension (e.g., “If I do not adhere my illness will get out of control”). They experience fear and sometimes terror when thinking about the consequences of non-adherence.

Being even better (“I know if I adhered more I would feel even better”). A sub-group of these patients (20%) associate adherence more with being “even better.” They adhere sufficiently or insufficiently, and they know that they could be healthier or have more energy, but they appear content with their current level of adherence, or say they do not know why they do not work harder for their health.

Autonomy (“I do this because if I do not take care of myself, nobody will”). Half of the HT patients (53%, n = 27) associate adherence with being more self-reliant and protecting their present and future autonomy. They value their independence and do not want to depend on the care of others. Also, they see their treatment as their own responsibility.

Affiliation. Many patients (73%, n = 37) experience adherence as a way of being closer to other people. There were three specific emergent voices: taking care of others, sharing with others, and being cared for. In general (58%), when these voices appeared, patients tended to adhere sufficiently or optimally.

Taking care of others (“I follow the treatment so I can be there for my loved ones”). Almost half of the HT patients (47%) associated adherence with being well enough to take care of others who need them. For some, it is actively taking care of children or grandchildren, while for others it is more about keeping healthy so they do not become a burden to others.

Sharing with others (“I adhere because I want to continue sharing with my family and friends”). A few of the patients (20%) declare that adherence brings them closer to other people. Some share healthy eating habits, others feel more active, and so can go out and meet their friends and family.

Being cared for (“I appreciate the care and concern that the medical staff and my family provide me, I will not let them down”). About a quarter of all HT patients (27%) associate adherence with being taken care of, feeling the doctor’s and family’s approval and appreciation. They feel grateful for that and do not resent others’ involvement with their health choices.

It’s not a big effort (“It is not difficult to follow the treatment”). Finally, about a third of the HT patients (31%, n = 16) express that adherence is not a big effort for them. They continue leading a normal life and do not feel anything special (fear, sadness) about the changes they had to make in their lifestyle. They think it was easy (e.g., “You just need to get used to it”), and some already had healthy habits. While 38% of the patients that presented this voice adhered insufficiently or dropped out, most of them (62%) adhered sufficiently or optimally.

**Table 2. Pro-Treatment Voices and Their Relationship to Patient Adherence.**

<table>
<thead>
<tr>
<th>Adherence Level</th>
<th>Self-Worth</th>
<th>Well-Being</th>
<th>Affiliation</th>
<th>Autonomy</th>
<th>Taking Care of Others</th>
<th>Sharing With Others</th>
<th>Being Cared for</th>
<th>Not a Big Effort</th>
</tr>
</thead>
<tbody>
<tr>
<td>Optimal</td>
<td>6</td>
<td>7</td>
<td>9</td>
<td>11</td>
<td>6</td>
<td>3</td>
<td>8</td>
<td>5</td>
</tr>
<tr>
<td>Sufficient</td>
<td>4</td>
<td>9</td>
<td>10</td>
<td>4</td>
<td>8</td>
<td>10</td>
<td>4</td>
<td>2</td>
</tr>
<tr>
<td>Insufficient</td>
<td>5</td>
<td>7</td>
<td>13</td>
<td>5</td>
<td>7</td>
<td>6</td>
<td>3</td>
<td>3</td>
</tr>
<tr>
<td>Total drop-out</td>
<td>1</td>
<td>4</td>
<td>1</td>
<td>1</td>
<td>1</td>
<td>2</td>
<td>1</td>
<td>1</td>
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<tr>
<td>Total</td>
<td>16</td>
<td>27</td>
<td>33</td>
<td>10</td>
<td>27</td>
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<td></td>
<td>1</td>
<td>4</td>
<td>1</td>
<td>5</td>
</tr>
</tbody>
</table>

In the following paragraphs, patients’ main anti-adherence voices will be presented according to their subjective meaning or adaptive function. These will be illustrated in
more detail than the pro-adherence voices because they are harder to explore in standard health care.

Eight anti-adherence voices emerged, which were classified into five broader categories (similarly to the pro-adherence voices). They are presented in Table 3 as well as their relationship with patient adherence.

Self-worth (“I am not weak or hypochondriac, so I do not need any special care”). For half of the HT patients in the sample (51%, n = 26), it is difficult to assume that they are ill or in need of special care. They associate having HT and fully adhering to being a hypochondriac, to being “different” from the rest, to 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 do not adhere to different aspects of the treatment: for example, the diet, exercise, medication, or they skip medical check-ups (e.g., to avoid getting another adverse diagnosis and feeling even weaker).

Patient 39: sufficient adherence

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

Patient: Weak people . . . I think those people expect others to do everything for them. I’m a Taurus, I’m close to my sign, I’m like [laughs] a bull, with maybe too much endurance. My husband is a weakling. “Ay, he says, I’ve cut myself,” but nothing happened to him.

Well-being. Many HT patients (82%, n = 42) associate adherence with some sort of decline in their well-being. Three specific voices emerged: anxiety regulation, quality of life, and Health (protection from iatrogenic effects).

Anxiety regulation (“Food is the only way I can manage my anxiety, so I cannot follow the doctor’s diet”). Some HT patients (27%) have difficulties regulating their anxiety and distress, so they use food as a coping mechanism. In these cases, adhering to the dietary part of the treatment would mean increasing their anxiety. They often take their medication but do not fully adhere to their diet.

Patient 31: sufficient adherence

I: Do you want to tell me about your attempts to follow a diet? Because I’ve heard you say that you’ve tried several times to lose weight but it doesn’t work and you do not know why.

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

Quality of life (“If I adhere more I will make my own life miserable and not worth living”). Most patients (67%) associate some aspects of the treatment with lowering their quality of life: enjoying life less, having an overly restrictive lifestyle, eating tasteless food, and being utterly stressed because of worries and having to control their longings all the time. A sub-group of these patients faced the following paradox: To control their HT, they need to worry about what they eat and their habits, but that increases their stress, and that consequently makes their blood pressure go up. Also, adherence is associated with military service, 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 do not adhere too much to the dietary and exercise part of the treatment.

Patient 46: insufficient adherence

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

P: From my point of view, they are strict, have organized schedules. I sometimes think, for example, they make small things very difficult. Sometimes they have the solution right next to 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 hypochondriacs . . . it’s like being too serious, being afraid of normal stuff you know? . . . Like my parents, I’m interested in them having 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?

Health or protecting from iatrogenic effects (“I will not adhere more because I fear the negative effects of the treatment”). Also around half of the sample (57%) have fears or have had direct experiences of iatrogenic effects of the medical treatment. Some of them reported having felt mistreated by medical staff, fear of becoming addicted to the drugs, or suffering side effects not only from the medication but also from the diet and exercise (e.g., mood changes or less energy). They tend to 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 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 that’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 . . . Some people go to the doctor because their nail hurts . . . 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 you know your own weaknesses . . . and besides you hear so many stories of malpractice.

Affiliation (“If I was alone I could do what the doctor ordered, but I am not alone”). For some patients (41%, n = 21), adhering to the treatment means setting themselves apart from other people, distancing themselves and sharing less. For most of these patients, adherence is more associated with not caring for others, for example, by forcing their family to cook without salt. For others, being ill is the only way of being taken care of by others. For the rest of this group, adherence means that they might be excluded from their peers or share less time with their family. For most of these patients, taking care of themselves means caring less for others, and they tend to prioritize the rest. They often take the medication but adhere less to the diet or exercise.

Patient 37: drop-out

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

P: [laughs] It depends, but it’s absolutely real that if you go to a group where everyone eats meat, and you come with your little lettuce, you allow them to make fun of 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”?

Autonomy (“I do not like to be slaved by the treatment or the doctor or anybody”). Just about half of the patients in the sample (53%, n = 27) associate adhering to the treatment with losing their freedom, living with too many prohibitions, and becoming dependent 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.” They usually “forget” to take their medication or avoid going to their medical check-ups.

Patient 30: sufficient adherence

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

P: The most difficult part was at the beginning, right? Eating without salt, taking two pills a day, I think when I forgot to take the pills it was a voluntary omission [mischievous smile] . . . Also, before it was like an obsession to check my blood pressure. I did it because the doctor had asked me to, 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 a slave of the little device.

Lack of motivation to adhere more. Finally, many patients (82%, n = 42) do not adhere because they lack motivation to adhere. In their case, it is more absence of pro-change voices than presence of anti-change voices that drives them to non-compliance. Two specific voices emerged: It is not worth the effort and hopelessness.

It is not worth the effort (“It is not necessary to adhere more”). Most of the patients (71%, n = 36), even though they do not adhere fully, state that they do not 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. They often 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 cannot help them, for example, because their HT is caused by stress and the treatment does not help with that. They usually do not adhere to the more difficult parts of the treatment, especially diet and exercise, and they only sometimes go for their medical check-ups.

Patient 48: insufficient adherence

I: So he told you to go to the medical check-up 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 others cholesterol, and again for others it’s the heart. I mean, it’s the age, for some this happens at 60, for others at 65, 70, something, some ailment you get when you get to a certain age. So I don’t worry, and you need to learn to live with your physiological deficit because that’s what aging is.

Hopelessness (“This is too much for me, it is not worth the effort because I just cannot”). This voice is present in a group of patients (25%, n = 13) that feels as though coping with the illness and making all the required lifestyle changes are too heavy a burden for them to handle. Some patients are facing depression, while others are so afraid of the diagnosis that they are overwhelmed by anxiety, and just thinking about the disease makes them feel hopeless and powerless.

In a sub-group of these patients (16% of the total sample, n = 8), this voice of hopelessness is dominant. They all adhere insufficiently 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 their self-efficacy improves.

Patient 28: drop-out

I: So after that you didn’t attend no more [medical check-ups].
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 shook, I almost fell. I didn’t want to go outside, I was afraid if I would go out and I would fall that 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.

Discussion

This study highlights the main motivations (or voices) of this group of hypertensive patients to adhere or not to their treatment. Results provide support to the notion that their resistant behavior aims to preserve important personal values: self-worth, well-being, affiliation, and autonomy (or just that more adherence is not worth the extra effort). These complement previous findings about patients’ reasons for non-compliance, such as the adverse effects of medication, distrust toward the medical system, fear of stigma associated with some illnesses and perception that their problems were not too severe (Lukoschek, 2003; Pound et al., 2005; Unson et al., 2003; Viswanathan & Lambert, 2005).

Results also show that almost every patient (96%) had some degree of ambivalence, or presence of both pro- and anti-treatment voices in their discourse. This supports Di Noia and Prochaska’s (2010) notion that patient ambivalence persists after the initial contemplation phase is resolved, but that change requires the motivations toward change to outweigh the motivations against it.

A topic in which our results differ from previous literature is in that patient adherence is usually considered a dichotomous variable (Ma, Chen, You, Luo, & Xing, 2012), while our results support the notion that adherence is a far more complex problem. There are patients who fully adhere to the diet aspect of the treatment but do not take the medication, whereas others take the medication and do not assist with the medical control sessions, and so on. Previous studies mention that diet and exercise changes have poorer adherence than medication intake (Martin et al., 2005). However, we did not find other studies that showed how patients adhere or non-adhere to different aspects of the treatment programs, depending on how they construct meaning to that particular activity.

Another important finding was that 41% of all patients interviewed who presented the well-being pro-voice (meaning that they knew adhering was convenient for their health and were motivated by that) did not adhere in a sufficient or optimal manner. Also, 20% of all interviewees know that adhering more would make them feel even better but still do not adhere optimally. These results show that having information about the illness and treatment is not enough to guarantee adherence. So, as previous researchers have argued, strategies to improve adherence should not be limited to psychoeducation and cognitive-behavioral interventions, but instead include underlying, implicit affective meanings (Creer et al., 2004; Haynes et al., 2005; van Geelen, 2010), such as the patients’ personal construction of meaning to each aspect of the treatment program.

As said before, there are many patients who know the benefits of adhering but do not change their behaviors. This reinforces the concept of intentional non-adherence (Lehane & McCarthy, 2007) and the idea that it is necessary to address the personal costs and benefits of non-adherence to the patient. The idea that each patient assesses the pros and cons of a particular health behavior is present in almost every health psychology theoretical model (Bosworth et al., 2006; Christensen, 2004; Munro et al., 2007). However, typical methods for assessing patients’ motivations for non-adherence focus on their
own conscious self-report, and this data collection method leaves more implicit or emotional schemas unattended.

In our research, it was crucial to use appropriate methods for exploring anti-treatment voices. For example, if the interviewer used a slightly judgmental tone in framing the question, or if he highlighted the importance of self-care, the anti-treatment voices faded into the background and were not reported by the patient. However, if with the same patient in a later part of the interview, the interviewer empathized with the common difficulties of adhering and explored the specific circumstances of non-adherent behavior, the anti-treatment voices could emerge into consciousness. Also, if the patient was only aware in that moment of the pro-voices, his own behavior was incomprehensible to him, and he resorted to rationalizations or explanations such as “I don’t know why I can’t do it” or “I just lack willpower.”

It is imperative to bring awareness to the patients’ anti-treatment voices, bringing them out of the shadows where they exert a powerful influence. Standard interventions do not try to understand patients’ worldview or implicit constructions of meaning, focusing instead on informing about the benefits of adhering and the many reasons to follow the treatment. This is because non-adherence is commonly perceived as something that needs to be challenged or fought against (Beutler et al., 2002; Bosworth et al., 2006; Christensen, 2004; Levensky, 2006; Meyer et al., 1985; Munro et al., 2007; Ortiz & Ortiz, 2007). This leads to a completely pro-adherence atmosphere, thus inhibiting the expression of anti-treatment voices, which are kept out of awareness. So, to have a positive influence on the patients, we need to understand them and speak their individual and cultural language (Fisch et al., 1982; Weiner, Nezu, Nezu, & Geller, 2012). If we know the personal values and beliefs that sustain their non-compliance, we will be able to motivate them more effectively, especially because in our results the same personal values that hinder adherence are the ones that motivate it (self-worth, autonomy, affiliation, well-being). Alternatively, this will allow caregivers to help patients adjust the treatment indications in a thorough and honest assessment of the overall benefits and risks, fostering a more cooperative and respectful relationship (Pound et al., 2005).

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**References**


**Author Biographies**

Pablo A. Herrera, PhD, is a professor and researcher in the University of Chile, School of Psychology, Santiago, Chile.

Laura Moncada, PhD, is a professor and researcher in the University of Chile, School of Psychology, Santiago, Chile.

Denise Defey, MA, is a professor and researcher in the University of The Republic, School of Psychology, Montevideo, Uruguay.