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# **Living with diabetes and hypertension in Tunisia: popular perspectives on biomedical treatment**

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# **Living with diabetes and hypertension in Tunisia: popular perspectives on biomedical treatment**

## **Keywords**

Tunisia; diabetes; hypertension; qualitative research; patient perspectives

## **Abstract**

**Objectives.** The growing prevalence of non-communicable diseases (NCD) across the Middle East and North Africa poses major challenges for underfunded health services. This article presents data on the perspectives of ordinary Tunisians who are coping with two of these diseases – diabetes and hypertension – and who are obtaining treatment through Tunisian public health clinics. Little has been written to date on patient experiences of biomedical treatment in Maghreb countries.

**Methods.** Based on qualitative methods and semi-structured interviews with 24 patients attending two clinics, one urban and one rural.

**Results.** We examine popular aetiological beliefs, ideas about biomedical treatment and its implications, and comparative views on the benefits and drawbacks of treatment in both public and private clinics.

**Conclusions.** We highlight two main themes. One was nostalgia for a recent past when ‘pure’ and ‘natural’ food, ‘proper’ meals and less stressful lives meant less chronic illness, with demanding and costly treatment. The other concerned communication in the clinic, and the recurrent dismay patients felt at what they saw as the cursory attention and guidance they received from clinic staff in public facilities.

## **Introduction**

Like many emerging countries experiencing pronounced social and economic change, Tunisia today is also undergoing a rapid demographic and epidemiological transition (Ben Romdhane et al. 2005; Mokhtar et al. 2001; Ploubidis et al. 2013; Wong et al. 2013). Tunisia is the most geographically compact of the Maghreb countries, with a population of 10 million, about one quarter of which live in the capital, Tunis. New dietary habits and increasingly sedentary lifestyles constitute well established risk factors for the rapid increase in major non-communicable diseases (NCD), like cardiovascular disease (CVD) and diabetes. Underlying these risk factors are broader processes of urbanization, with accompanying changes in patterns and conditions of work, and a decline in extended family living arrangements. In Tunisia, levels of both CVD and diabetes are estimated to be highest in the relatively more affluent coastal areas (Ben Romdhane et al. 2002; Elasmî et al. 2009). Meanwhile, health services, developed to tackle acute infectious diseases, struggle to cope with the surge in non-communicable diseases. NCDs have become the leading cause of death (Ben Romdhane et al. 2012; Saidi et al. 2013).

Although these diseases are now a major public health problem in Tunisia, little has been written about the knowledge and understanding of the wider population, particularly patients themselves, regarding these illnesses (Tinsa 2011 is a rare exception). Worldwide, an abundant literature now exists showing how ideas about disease causation and treatment embody wider cultural and moral values concerning the nature of health, well-being, social relationships, or life itself. Some of that literature is specific to Turkey and the Middle East (Adib 2004; Dole 2004, 2006; Good and Good 1992; Mateo Dieste 2012; Spadola 2009; Yehya and Dutta 2010). However, this literature largely emphasises the continuing importance for certain groups of healing practices which lie outside biomedicine and have a religious and ritual aspect – therapeutic practices which are largely invisible to the state and biomedicine. There is little literature from the region exploring popular perspectives on the experience of biomedical care or the quality of clinic treatment, although Giacaman on Palestine (1988) is an exception, while Morsy on Egypt (1988, 1993), and Obermeyer (2000a,b) on Morocco reveal the ways that biomedical and ritual forms of treatment may be interwoven in people's lives.

In this article, we present evidence from a recent study to explore the understandings held by ordinary Tunisians coping with diabetes or hypertension, or both, who are obtaining treatment

through Tunisian public health facilities. We cover urban and rural contexts, and include examination of popular aetiology, and ideas about biomedical treatment and its implications. This article arises from a cross-national comparative research project on the preparedness of health systems in four Mediterranean countries to cope with the increase in diabetes and cardiovascular disease, and the ways in which health services for these medical conditions were provided (Phillimore et al. 2013). This project, known as MedCHAMPS and funded by the European Commission, took place in Palestine, Syria and Turkey in addition to Tunisia.

## **Methods**

Data collection for MedCHAMPS took place in the year preceding the tumultuous events which have transformed the region, and which started in Tunisia itself at the turn of 2010-11. Such a study would have proved impossible to undertake a few months later. MedCHAMPS' focus on health service provision and health system preparedness was complemented by a major epidemiological investigation modelling disease trends and projections (for study design, see Bowman et al. 2012; Maziak et al. 2013). The investigation of health services and systems focused partly on specific regions within each country: in Tunisia, this meant a focus on Tunis itself and on one rural area. The analysis presented in this paper draws on data collected as part of this region-specific element of the study.

In analysing the organisational structure of the health system and the reality of health service provision, the research design distinguished three 'levels': a level of conceptualisation, relating to formal national planning; a level of awareness, relating to the attitudes and knowledge of senior figures responsible for implementing policy; and a level of practice, which examined how health policies and provision actually worked in selected clinical settings. This third level was the area-specific element of the study; and, in order to gain a rounded view of local practices, it synthesised the perspectives of both clinical staff and patients (and family members). It is this third level of the research that we draw upon in this article, using primarily the interviews which were conducted with patients or family members and with clinic staff in two government-run primary health centres (one in Tunis, one in a rural setting). We also draw on data from limited observations of practice made in these health centres. All data were collected during the first nine months of 2010, after obtaining national ethical approval.

Twenty-four patients with diabetes and/or hypertension were interviewed, twelve of each sex. These were drawn from patients attending these two public clinics on a particular day (twelve rural, twelve urban). Their ages ranged from mid-40s to mid-80s. Both clinics catered primarily for relatively poor neighbourhoods and populations. Sampling was purposive, but adapted to necessity given the challenges and novelty of original qualitative data collection in Tunisia. We sought and achieved a balance of both conditions under study, diabetes and hypertension. What a small sample like this could not adequately do justice to, was the potential variability between urban and rural lives, in terms of literacy and education, or knowledge and expectations of clinical treatment; nor the variability in generational experience between those in middle age and those who were much older. Similarly, we could not claim to reflect differing perspectives relating to the stage or severity of the disease. Nonetheless, the study design affords an insight into some of the contrasts and similarities across location and generation in an area of the world where little research has so far been done on patient perspectives of clinical treatment. A subset of twelve family members was also interviewed. These were largely spouses of patients; a minority were adult children. The perspectives of spouses revealed few differences from those of the patients they accompanied (in the case of adult children accompanying patients, numbers were too small to indicate possible contrasts in viewpoints). A small separate sample of clinic staff was also interviewed: two specialists, two family doctors, and two nurses, selected from the clinics whose patients were interviewed. All interviews followed schedules which were designed for use across the MedCHAMPS project. Data was coded using the qualitative analysis software ATLAS.ti.

## **Results**

***Making sense of symptoms and causes.*** Although initial symptoms may not immediately be associated with a particular illness in a person's mind, signs of physical dysfunction imply the possibility of illness. This is the commonest reason for a consultation with a doctor, and seeking medical treatment was the first course of action for those we interviewed – both for diagnosis and subsequent treatment. Family members may play a supplementary role also at the onset of symptoms, encouraging clinical consultation. While the healthcare system remains the primary starting point for the treatment and management of illness, there were individuals who chose to try – or indeed advocated – supplementing medical treatment with the use of herbs, or particular foods (garlic, olive leaves), while a few professed the value of scarification

to help control blood glucose. In each case, these did not replace medical treatment and guidance. No-one in our sample claimed to have sought the aid of 'traditional' healers. While such a possibility was usually rejected, on the basis that such healers lacked adequate training or appropriate skills, a number of people admitted that they could understand why others might turn to them, if consulting such practitioners provided comfort and support.

We distinguish three different kinds of cause that interviewees mentioned. These were not mutually exclusive, though usually one received primary emphasis. The first, and most commonly cited (especially in the urban context), reflected the current dominant discourse in public health in focusing upon inherited predispositions and 'modern lifestyles', highlighting a poor diet rich in fatty and sugary foods, and the frequent lack of physical activity. The views expressed here were widely shared if rarely so confidently asserted.

First things first: it can be hereditary, it can come from a family member, from the father or mother. Or of course, diet, a poor diet, a lack of physical activity. Things like pasta, heavy pasta and couscous dishes... all those foods that are rich, fatty and that kill the body. (Man, 54 years, urban)

Another interviewee affirmed that there was little stigma attached to having diabetes.

Everybody knows. When someone gives me something sweet, I just refuse. What I say is that I have a factory of sugar. I am diabetic and everybody knows that. It is not a secret, it does not matter to me if they know or not. (Woman, 62 years, urban)

But what is the explanation for the modern unhealthy lifestyle – the cause of the cause?

Interviewees were not slow to make a connection between diet, physical exercise, and the character of modern life, including its speed or pace, its relentless pressure, and the stress that induces. Thus, alongside reference to the acknowledged need for lifestyle changes, they also spoke of everyday stresses and strains, linked to talk of a change in the character of the times. Interviewees spoke of the recent past when food was healthier, because it was recognised to be more 'natural'. Much of the modern diet was portrayed as somehow 'contaminated', rendered 'unnatural' by the incorporation of chemical or artificial additives.

Who can avoid it? Maybe one who lives alone and does not have any contact with society. If you live in society, how can you avoid the disease? (Woman, 62 years, rural)

The same impulse contrasted a past in which physical activity was woven into the fabric of daily lives with a present requiring the constant stress of demanding time management, of workloads and other hitherto unfamiliar constraints of everyday modern living.

Maybe it's the stress that we know nowadays. Maybe it's the food that's not as good. We used to go into the fields and the food that grew there was good. Now it's full of chemicals. I've experienced the life we had then and I'm experiencing the life of today's world. There are so many things that have changed. It's not the same. (Woman, 70 years, urban)

Changes in family structure were also adduced as factors which added to stress. The shift towards a nuclear family structure was seen to increase responsibilities which formerly could be shared among kin. Women cited this as a source of increasingly stressful lives, and were more likely to hold family and domestic pressures as causing the stress which contributed to their ill-health. Men by contrast were more likely to blame pressures at work and to see themselves as carrying the greater stress. But either way modern living was identified as a prime cause of the causes:

The man is responsible for everything. He thinks about everything, he works, he tries to do the necessary for his wife. Women are protected. (Man, 68 years, rural)

Women tire a lot, a lot – the childbirth, the work, she thinks about her children, she goes to work and she leaves them. The man, no, even if he tires, he is a man, he is the basis, and the brain, it [stress] does not influence him like it does a woman... The woman is easily touched and now she has a larger responsibility. (Woman, 70 years, urban)

A second kind of explanation alluded to the role of a divine fate. One woman (rural) warned: "The causes are divine. It is a warning from God." Another (urban) suggested that God's will meant there was little a person could do: "a person shouldn't worry because it is God who gives you the disease and he heals you". The centrality of religious beliefs for some, especially women, did not supplant medical treatment. Religious beliefs worked at another level, offering an ultimate explanation beyond connections of cause and consequence known from medical advice.

A third sort of explanation for these NCDs was highly personal, invoking painful hardship or disturbing life events. Occasions of traumatic loss and grief were often seen as being a psychological trigger for subsequent symptoms, while being overcome with anger (*ghoch*) or sudden fear (*fajaa*) were also perceived as possible causes which could trigger disease.

I had a very hard life, I could not study, my parents are dead and my brothers did not let me study. I had to work in the fields, it is too hard – this is why I have diabetes now.  
(Woman, 45 years, rural)

***Adjustments to illness.*** Reactions varied to diagnosis. Some patients were overwhelmed with feelings of resignation; others spoke of fighting the illness and did not want to allow it to defeat them.

Especially at the beginning, it is like a great catastrophe, everything has changed. Afterwards, everyone reassures you: they say it is like a bad friend who will live with you, but it is not dreadful. (Man, 56 years, urban)

Having either condition was seen as a definitive break with their previous state of being: "it's not like before" or "it's destroyed me" typified such comments. Nearly all patients spoke of greater irritability. Family members with caring responsibilities seemed to agree, alluding to the stress they faced as carers:

Sometimes he argues for nothing, especially these days. With ageing, the disease becomes complicated. He does not want us to talk with him, because he becomes angry easily. It makes me ill. I'm always worrying about him. I try to do my best but I don't understand him anymore. (Wife of man with diabetes, 45 years, rural)

Indeed, family relationship problems were considered the most serious of the social costs of ill-health, and anxiety about the risk of jeopardising these crucial relationships surfaced repeatedly. Interviewees on occasions referred to a vicious circle: increased irritability could exacerbate family tensions; but existing family stress could in turn cause irritability. Patients typically believed that relationship problems were accentuated by having diabetes or hypertension, and that changes in both their mood and character played a part. In addition, concerns about sexual functioning were commonly voiced among the men we interviewed (though not the women).

***Patient views about clinic care and communication.*** Our data suggest a mixed picture of treatment received in clinics – both the quality of service and the attitude of health personnel. A lack of communication on the part of both doctors and nurses was the main criticism voiced. Doctors especially were perceived as too rarely giving sufficient time and attention to listen to patients. Not only was this seen as disrespectful to the patient, displaying a lack of human understanding and compassion; it was also seen as medically counter-productive, making it harder for the patient to learn about the progress of their disease and the treatment expectations of the clinic. The intermittent and anonymous nature of relationships with doctors compounded these problems. Patients sought a more personal relationship with doctors – which they knew they were unlikely to get. As one woman said:

The person is sick, not just physically but psychologically. If you are not patient and receptive, if you do not talk to her, you do not see what she has, how can she feel better? They go home feeling worse than before. (Woman, 70 years old, urban)

Patients complained of cursory consultations reduced to an emphasis on the drugs to be taken, and lacking in emotional support. Nurses fared little better in patients' judgement, for although they were viewed as less remote than doctors, their empathy was similarly seen to be limited. Indeed they were commonly regarded as intimidating and inconsiderate.

Yet this judgement needs to be qualified, for criticism of staff attitudes in public health clinics was more pronounced in the urban than the rural context. Rural patients spoke of how they knew their nurses and even doctors, and were more likely to speak of continuity in their relationship with clinic staff. Yet we cannot discount the possibility of greater reticence in rural areas about voicing criticisms of an authoritative local institution, on which everyone necessarily depends, and where alternative options do not exist (as they do in cities).

In the city, treatment in public facilities was commonly compared unfavourably with treatment in private facilities, even if an undercurrent of criticism of private clinics is that they 'care about money'. Above all, it was commonly held that in private clinics staff give time to listen properly to patients.

The education of the doctor, his humanity, that's what we don't find in the public hospitals. I would like the behaviour of the nurses to change, that they do their duty. Why

do the private doctors follow you well, listen to you, and the other [doctors], no, that's what I do not understand? (Woman, 70 years, urban)

While patients (and their family members) had expectations of the health facilities they relied upon, they also understood that the clinics had expectations of them. Interviewees knew that their clinic expected them to adhere to advice and to prescribed medication. Yet knowing this did not always help, because patients were often left unsure exactly what was required, for reasons indicated above. Even when patients understood precisely what they were meant to do, economic hardship might undermine good intentions.

***Clinic staff perspectives on patients.*** Health personnel had their own views about the knowledge and behaviour of the patients and families they saw. Often these views were judgemental, highlighting patients' 'ignorance'. At the same time, nursing staff in particular often belonged to the neighbourhood where they worked; they shared the same values and expectations about illness and medical treatment as those they treated. From the point of view of a doctor or senior nurse, however, adherence to treatment guidelines required no more than the patient's attentive listening. The time for consultation that the patients sought was seen as neither practical nor appropriate. A vivid illustration came during an observation in the rural clinic. One patient told the doctor that he had been monitoring his condition carefully since his last appointment, and had managed to reduce his medication. It was evident that this patient believed he had done what was expected of him: he had taken responsibility for his condition. This elicited a fierce response, however, from the doctor, putting the patient in his place with a comment that "you are not the doctor, what permits you to make these decisions?"

Some clinic staff conjured up an image of the 'negligent' patient, someone who was portrayed as sufficiently educated to know what was required of them, but who apparently wilfully disregarded the guidance provided. But this critical viewpoint was also balanced by recognition of factors which made adherence difficult. Only one nurse spoke of the importance of trust between staff and patient in managing chronic conditions. But other health staff alluded to patients' understandable ignorance of the risks of complications that accumulated with time, as well as the problems of sustaining patients' motivation. Staff knew that this problem was compounded by the negative portrayal of certain products like insulin, or the prevalence of beliefs among some groups that diabetes may be cured by herbal remedies (not something that

was admitted to by our own patient interviewees). Indeed, complications of diabetes posed a considerable challenge, as one doctor noted:

When a patient has a complication, it is really very difficult to live...someone who has lost his sight, it's not easy; someone who is on haemodialysis, it's not easy. That's what frightens me the most.

Financial difficulties were also recognised by some we interviewed as the biggest problem for patient adherence. Poorer patients who did not have the financial capacity to pay out in advance were said to avoid such costs arising, to the detriment of their treatment. Although Tunisia's health insurance system is often regarded as one of the most comprehensive in the region, the delays to reimbursement were widely seen as posing major problems. Loans from family members or staggered payments to pharmacists were the 'solutions' our informants mentioned as necessary consequences of these delays. But there were also acknowledged to be problems due to the funding of the health system itself, for as one doctor stated: "We always ask the patient to take his drugs, and we are always saying to him never to stop. But then we say to him, 'no, we don't have [these] drugs, come back tomorrow.'"

## **Discussion**

The study on which this account draws was small in scope and exploratory, relying on methodological skills which are still rare in Tunisia. We therefore hesitate to draw more than tentative conclusions from it, particularly for policy. It is also important to acknowledge that the design and focus of this study imposes its own biases. It would be easy to conclude from the data presented that patients rely almost exclusively on biomedicine. Yet we should be cautious. As we noted, literature from the wider region is a reminder that treatment-seeking practices can lead patients to try alternative kinds of therapeutic option outside biomedicine. Our design, seeking patients already being treated in a clinic setting, potentially biases this study towards those predisposed to seek biomedical treatment. Recruitment in the clinic setting may also have inhibited these patients from speaking of any alternative paths to treatment they may have tried. Such individual silence is, moreover, encouraged by the language of the state (at least up to 2010). For state-led discourse equated modernization with the sweeping away of practices seen as 'outdated' or 'backward' in fields such as healthcare

(cf. Morsy 1988, 1993). In such a context, alternative therapeutic practices become at best less reputable than ‘modern’ medicine, and at worst invisible.

Recognising these limitations of design is not to diminish the value of the insights we present here. Qualitative investigations of patient experiences of biomedicine remain rare in the region (although see Morsy 1988, 1993; Obermeyer 2000a,b), and this article highlights what is gained from attending to popular views on biomedical treatment and judgements of clinic care. In concluding this analysis we highlight two recurrent themes in our data: one relates to nostalgia for what is seen to be lost with modern lifestyles; the other concerns communication in the clinic.

Evident in our interviews was reflection on the perceived relationship between ‘tradition’ and ‘modernity’. For most of the patients we interviewed there was a palpable sense of loss, nostalgia for more straightforward times. A large social scientific literature exists on nostalgia, and its association with the ambivalent experiences people everywhere have of modernity. Turner (1987) and Boym (2001), for example, have explored how nostalgia has become a leitmotif of the experience of modernity almost everywhere. The connections made by those we interviewed between diseases like diabetes or hypertension and modern lifestyles provided fertile ground for nostalgia. The peculiarly stressful character of modern life, including a new awareness of time as a source of stress (the lack of time, demands on time, time devouring things) was seen to cause or exacerbate these diseases, which were in turn viewed as ‘modern’ diseases. Patients knew that physical activity was important as a way to manage and mitigate their impact; but time pressures and the rhythms of modern working life worked against the injunction to take exercise. Changes in diet and the quality of food was equally a focus for nostalgia. Food had ‘deteriorated’ and become ‘contaminated’ by chemicals and processing. Food was described as less ‘natural’ than formerly, thereby standing for a wider sense that life in general was less ‘natural’ than it used to be. Thus the clinical encounter, and its implications for the lives patients are advised to lead, seemed to evoke a powerful sense of nostalgia.

A second theme has a more direct bearing on health policy and clinical practice, and concerned communication. Patients were continually frustrated by what they experienced as the perfunctory and sometimes brusque attention they received from clinic staff. Health personnel in turn were frustrated by what they saw as the inattention of patients to medical advice and instruction. Time was invoked in this context also, a source of contention for both sides: clinic

staff feeling pressured to see patients briefly; patients feeling that their own needs were accorded too little time. We suggest that this frustrated social dynamic offers a powerful illustration of the commonplace human expectation of, and demand for, recognition (Ricoeur 2005) – coupled with the sense of indignity that accompanies persistent *misrecognition*. The need for one's voice to be heard is a claim for respect and mutuality, made all the more urgent for patients by the insecurities of facing up to limiting and potentially life-threatening disease. Patients looked for small ways to lessen the perceived distance between themselves and key clinic personnel – a distance created by the brevity of consultations, the one-way exchanges they involve, and the anonymity of most clinic experience. By contrast, few health staff showed interest in reducing this distance. For them, patient expectations needed to be channelled into what was realistic, the transmission of key information to assist the prospect of adherence. A single nurse acknowledged the importance of catering to patients' needs for empathy. Patients in their turn rarely complicated their treatment by voicing these disappointments to clinic staff. Yet we stress that such thwarted communication is more than personal frustration; it is rooted in structural arrangements which make it all the more intractable.

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