

### Denial in two voices. The power of storytelling

Dr Santos couldn't help a little involuntary shudder as he cast his eyes over the patient list. Arlindo Cardoso ....

When they had last met Santos was looking at the dessert menu in a busy restaurant. Driving home from a diabetes clinic in a nearby rural village that Saturday morning Santos had seen the signs for the *Arraial dos Petiscos* and his stomach reminded him that he had not eaten. The restaurant had been a choice by necessity rather than preference. After all he had just wanted a little respite. However, that was not to be as Arlindo burst in in ...

"Ah! Dr Santos, I see you like desserts too... Who'd have thought?"

"Arlindo, what an unexpected surprise to see you here," was the only rejoinder Santos could think of at the time.

"And why shouldn't I be here?" came the quick, slightly defensive retort. "And what are you doing here, doctor? Checking up on your patients?"

Santos's knew his simple explanation would not satisfy Arlindo, so he played along. Raising his hands in mock surrender to show that he didn't have a glucometer hidden under the table. Satisfied, Arlindo replied with a twinkle in his eye!

"Then you must try the 'Death by Chocolate' – it's the best!"

"Arlindo..."

Dr Santos's reply was greeted by grins and some laughter from the nearby diners. The restaurant catered to a regular crowd, and obviously Arlindo was well known so the exchange was being closely monitored.

However, despite his playful comments, Arlindo Cardoso was very careful about his diet. Diabetes had dogged his family. It seemed to be part and parcel of their very being, his grandparents, his parents, almost all his uncles, most of his siblings and cousins had suffered from diabetes, oftentimes presenting severe clinical complications. Arlindo was under no illusions, he *knew* he had to follow medical advice and be careful about his diet, and he complied generally. But verbal sparring was also part of his nature and so he continued.

"But be careful – remember it's just one helping at a time!!!"

"If I didn't know you Arlindo..."

"Don't worry, Dr Santos, I've learnt my lesson. Look, here are my boys..."

And he pointed to two slim, fit-looking young teenagers who had been trying to avoid their father's attention. Obviously embarrassed at his carping they made for the door.

"...don't they look well? I keep an eye on what we all eat, not too much pudding in my house. But then, who needs dessert when there's someone as sweet as me at home!!!"

When the boys had gone Arlindo turned to the woman with him: "And look here at Deolinda... my sister, the only one in the family who has never shown the slightest inkling of diabetes..."

Not sure how to answer this onslaught, Santos mumbled the only thing that came to mind "Congratulations Deolinda, that's wonderful news, keep up the good work..."

"Congratulations, congratulations... Congratulations, my foot! She says she doesn't have diabetes because she doesn't want to do the blood tests... if she did, we'd see..."

"I tell you, doctor, some people don't want to face facts! Something bad is going to happen to her and we'll be left holding the baby! She has diabetes for sure, and as you know there's no fooling around... doctor, talk to her, talk to her, try to convince her... She's a ticking time bomb. If she wants to kill herself, what can I do! But doctor... she's my sister..."

In the face of this torrent Deolinda's deafening silence spoke volumes. Her expression – aloof and numbing as she examined of the two wolves carved into a wooden cabinet – snuffed out all possibility of conversation. Mutely, she proceeded to the door to join her nephews. Finally, her brother followed, with a final salvo. "Enjoy the rest of your meal, doctor, and if you ever come back here for lunch let us know!"

After hurricane Arlindo departed, the eyes of the restaurant were all on Santos. As he finished his meal under their watchful gaze, he swore never again to return to that restaurant.

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Waiting for Arlindo, Dr Santos was thankful for the quieter atmosphere of the consulting room at the Diabetics Association. He also hoped this would induce a quieter version of his patient. But this was not to be. When the door opened, hurricane Arlindo burst into the room accompanied by none other than Deolinda. The latent energy, perhaps garnered by the enforced silence of the waiting room, was palpable, choleric; his whole body seemed to shake in his sister's direction. Nothing could stay his words now!

"Didn't I tell you?! Didn't I tell you?! She has diabetes! Still, I had to drag her here! She didn't want to come, can you believe that? She did not want to come! "She said she didn't have diabetes, she didn't have diabetes! It took a stroke! I found her with her mouth sideways... a stroke... they did a CT scan and that proved it... and her blood sugar, her readings were off the charts – four hundred and fifty-seven! Four hundred and fifty-seven!"

In the midst of this outburst, the accused maintained her habitual, detached silence. Her own story did not seem to interest her.

"At least she did her physiotherapy... She has regained her speech and she's moving quite well. But Dr Santos, she doesn't want to do anything else. She has no interest in checking her blood sugar level. She won't do stick checks, or take the medication or the insulin they prescribed for her at the hospital! She didn't go to her appointment with the specialist and didn't even tell us that she had skipped it! If it hadn't been for Firmino I wouldn't know what she had done. She just did the physiotherapy... If it hadn't been for Firmino she would still be trying to carry on the same as before... I had to drag her here!"

I didn't know who Firmino was, but I wanted to hear Deolinda's version of the story.

"Deolinda – may I call you Deolinda? – you know if you have diabetes you have to take care of yourself, you have to do tests, follow a treatment program so that we can monitor your progress... we need you to do this so that we can decide what the best course of treatment is for your case."

Deolinda fixed Santos fully in her gaze for the first time. "Dr Santos, look! As long as I do not start a course of treatment, I do not have diabetes."

Arlindo put his hands to his head in desperation.

Trying to reason with her Santos intervened, "But Deolinda, the only explanation for your blood sugar levels is that you have diabetes. Your results are so high that there is no other possible answer... you have to be monitored..."

"I'm not interested in any of that! I only have one thing to say: I will not have diabetes until I start a course of treatment. And I do not want to have diabetes!"

And with those words she got up and left, Arlindo blustering and gesticulating in her wake.

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Denial. It is not easy to overcome denial, but it is fundamental for treatment. Despite his ham-handed methods, Arlindo's heart was in the right place, he wanted to help his sister, but his bravado was not helping.

Also, in her own way, Deolinda professed a great truth – it is only possible to treat a disease if patients accept the diagnosis. If they deny its existence, the attempt to control it cannot begin. *That is a doctor's dilemma.*

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Leaving Dr. Santos' Consulting Room Deolinda raised her finger as she saw Arlindo about to continue his tirade. "Not one more word out of you, I have heard everything I want to hear from you. Leave me alone. I'm going to get the bus home."

Without another word, Deolinda turned the corner leaving Arlindo opening and closing his mouth like a fish out of water. Still, she did not go to the bus stop immediately. Instead, she stopped in the nearest café; she needed to collect her feelings before she continued. She ordered a coffee and started to rant silently at herself.

"Why did I react like that to Dr Santos? By all accounts, he's a good doctor and he seems nice. I should be happy to have someone like him to help me. But, no I was dumb. I'm not usually so rude to people who are trying to help me. But..."

That "But" was so enormous Deolinda didn't even know where to start to begin to unravel the feelings that had led to her explosion. Silence had always been her tool, but even she realized the time for silence was now over. But what to do? She would have to quieten her mind to hear her thoughts, to start to understand.

Deolinda decided to return to a habit she'd had when she was younger. With few outlets for the rages of a middle child – a girl growing up in rural Portugal in the 1960s still under Salazar's paternalistic dictatorship – Deolinda used to write letters to the injustices. This had helped her face them: both real and imaginary. It hadn't solved her problems, but it had made her feel better. More than anything else this writing had allowed her to understand what was going on in her heart and mind, and she needed this desperately now. So, she decided to write one of her letters to Dr Santos, this pleasant, mild-mannered physician, who for some reason had angered her even more than her know-it-all brother.

"Doctor dear doctor, why did you irritate me so?" Surprised, now that she was looking at things a bit more objectively, she was able to unravel the source of her rage. It began when he asked her 'may I call you Deolinda?' When he proffered those words, she felt he wanted to know about her – her – and not her malady, and at that moment she was ready to talk to him, to hear him, to listen to him. But it was only for a fleeting moment, because then he motored on to tell her about her disease, he lost her. Not only did he lose her, but he also hurt her because he had given her a hint of hope and then he dashed it. She knew the window of opportunity was a small one, but her heart had skipped a beat when it had opened.

Stupid man – sorry for cursing at you, but dashed hopes can be hard to deal with. Why do men think they know more than the rest of us? Maybe it's not men, to be fair I'm sure a woman doctor would have treated me in the same way. She'd have also tried to tell me about my disease, explain its symptoms and consequences, but don't any of you realize I KNOW I HAVE DIABETES? How could I not know, I was the one who watched my mother grow old before her time as she was crushed under the burden of caring for a young family, ailing parents and the onset of disease. So while Arlindo was *praised* for being the life and soul of the brass band and the

athletics club, I gave up ballroom dancing to make things easier for her. When food and cooking were her only comfort, I was the one who tried to lighten her load. I noticed her change – I recognize the onset of diabetes.

The stroke frightened me, frightened me more than I'll ever admit because it made me see that my life might end before I have really begun living it. So, yes I am angry because I just want to live for a little while on my own terms. Part of that living is denying. I know it makes no sense, but it helps me, it gives me some kind of control, because I will be the one to decide when I start living the life of a diabetic.

Writing this I see also that I have had some luck, too. In his own way, Firmino seems to understand what I need. And I can trust him, even if I'm still a bit mad with him for talking to Arlindo. But he was desperate to get me real help; we both know that I have diabetes. Still, he didn't force me to go to the specialist or to come here. But he knew I needed physiotherapy. I had to remove the physical traces from my mirror – this I had to do.

Today, part of my living is denying what is wrong with me. The more I write, the more I realize that this is dangerous. But giving up on my chance to have some control over my life seemed even more dangerous before. Life can be a bitch at times and this diabetes appears to be my bitch. *I do not want to live my last days as my mother did!!!* Suddenly I realized that this was my great fear, maybe has always been my great fear. But now I realize I am not her, I never was and never will not be her.

Dr Santos, I must become a patient on my own terms, not on Arlindo's, not on yours, not on even the terms of my repressed and entrenched fears. And I do not know what this journey will be like, but if I go back to you, it will be with Firmino and not Arlindo. When I do will you help me? But Doctor, if you want to take care of me, *take care of me, ask about me and not my disease.*

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### **Commentary to 'Denial in two voices. The power of storytelling'**

The characters in the story are fictitious. Those in the first part are drawn from the first author's experiences of working in the Portuguese Diabetics Association. A version of this part of the story was published in the first person in Portuguese in the collection of short stories *Nem de Um Tipo Nem de Outro: Contos com Diabeticos* (Edições Lusociência, 2009). The second author, an Irish national living in Portugal, was asked to translate the original text into English. However, as she worked on this translation the character of Deolinda spoke to her, and she felt she had to give her a voice. Thus, the second part of the story was born. While Delinda's response is also based on the observation of real-life situations, the world of fiction allowed for an exploration of possibilities, not permitted by life writing.

We consider this short story is relevant to the field of the Health Humanities because it will bring readers into the world of those facing a diagnosis of chronic illness. It will allow them to reflect on the motivations that may underly an individual's decisions to follow destructive courses of action when faced with this diagnosis and, also the dilemmas those attitude provoke among healthcare professionals, as well as patients' families.