I recently had to spend many hours in the vehicle licensing and testing centre at Ottery in Cape Town while sorting out merged ID numbers (as a result of finally getting South African citizenship after living here since 1981) and getting a temporary licence in the meantime. I was dealt with efficiently and pleasantly, but the process inevitably took time. During that time I was approached by several people who were waiting in the various queues who asked me to fill in forms for them. They were obviously illiterate, either totally or to an extent that made filling in a licence application form impossible.

I know a few people who are at best semi-literate – one of them has a matric and runs his own business. But I know that, however successful these people are in their daily lives, an inability to read, or sometimes to be able to read but not actually understand what the words mean and act on them, is a real problem.

One of the articles in this issue of CME deals with the problems experienced by patients in resource-poor areas in dealing with type 2 diabetes. The author describes very well the problems raised by limited clinic hours, limited availability of the patients’ own doctors and the problems of educating people about what is a very complex disease. What he does not touch on is the fact that most of these patients will effectively be illiterate and what this illiteracy does to their ability to understand the management of their illness.

A recent paper in the New England Journal of Medicine does just that. It describes a 64-year-old diabetic man with ‘a history of noncompliance’ according to the resident who referred him to the specialist. He hadn’t taken either his diabetes or cardiac medication for weeks. The specialists were unsure why this was as he appeared to be intelligent and interested in getting well and he was able to have his prescriptions filled. Before he went home they explained to him why he needed to take his medicines and reviewed the frequency and doses with him several times. He told the specialists that he would follow up with his doctor, although he couldn’t remember the doctor’s name or telephone number. He left the hospital with a handwritten discharge summary. He appeared at the community clinic 5 months later. He said he was taking his medications but he wasn’t sure of their names or how he took them. His regimen was reviewed by the specialist and a medical student again. The student typed up simple instructions in large letters, as well as a list of dates and times at which he should record his blood sugar and he was asked to come back 2 weeks later.

When he came back he was seen first by the medical student – who made a diagnosis that no-one had previously thought of: illiteracy. The clue apparently was the jumbled mess of the glucose log. He was asked to read the list of his medicines aloud and could not. The patient was born in the rural south, had left school in second grade and lived alone. He supported himself as a garage attendant and general handyman, but he had never learned to read. The doctors were stunned. No-one had ever suspected that this man could not read – even though he had been seen by plenty of social workers and health professionals over the years.

Apparently about 14% of Americans have a ‘below basic’ level of ‘prose literacy’. Prose literacy is the ability to use written material to ‘achieve one’s goals and to develop one’s knowledge and potential’. Below basic is defined as being from no more than the most simple and concrete literacy skills to total illiteracy. Those with the ‘simple and concrete’ literacy skills can probably read sufficiently to understand written instruction on what to eat or drink before a medical test but will not be able to understand a pamphlet on what type 2 diabetes is and how it affects the body, for example.

If this level of illiteracy is as high as it is in the USA just imagine how poor many of our own patients’ literacy skills are. And then look at the number of educational materials in our clinics that consist of wall posters, pamphlets and written instructions. Then add in the fact that English is most people’s second or third language and look around you again. What real hope have our most disadvantaged patients in understanding health information, HIV prevention campaigns and how to take their medication? The people doing the eye testing at the Ottery centre were showing infinite patience with the obviously illiterate licence applicants. I unfortunately haven’t always seen the same levels of patience in our clinics.

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