The language of diabetes

Dr Eugene Hughes
General Practitioner, The Esplanade Surgery, Ryde, Isle of Wight, UK

Correspondence to:
Dr Eugene Hughes, General Practitioner, The Esplanade Surgery, Ryde, Isle Of Wight PO33 2EH, UK; email: eugene.hughes@gp-j84005.rhs.uk

This paper was presented as the 2013 Mary MacKinnon lecture at the 2013 Diabetes UK Annual Professional Conference held in Manchester

Abstract
The worldwide epidemic of diabetes shows no sign of abating. It is an international condition, with China set to become the diabetes capital of the world within the next decade. However, even within the UK, all the agencies involved with people with diabetes struggle to speak the same language. Health care professionals from all disciplines fail to communicate effectively with their target audience. The language used in the consultation can have a lasting impact on the direction of care. And at an organisational level, communication between professionals in primary care and secondary care is often poor and even divisive. Above all, the policies shaped by successive governments are couched in a language which suggests commitment and coherence, but which ultimately suffers from the confusion of Babel.

This presentation highlights the translational difficulties that exist between the different diabetes tribes, and urges a dialogue that transcends personal, professional and political barriers to effective and therapeutic communication, which will improve the lives and the care of people living with diabetes. Copyright © 2013 John Wiley & Sons.

Practical Diabetes 2013; 30(9): 358–360

Key words
language; collaboration; communication; policy

This is a language course. Pay attention!

Lesson 1
If you go to France and you don’t speak French, here are a few tips...
1. If people try to speak to you or explain something, just ignore them.
2. Pronounce what few French words you possess as though they were written in English.
3. Ignore graves, acutes and other unnecessary embellishments, especially cedillas.
4. If you don’t get what you want, just shout.

This is best illustrated by an incident involving my good friend, Colin, a jolly, somewhat outspoken Welshman. We were travelling through France on a ski-ing trip, and broke our journey at a hotel near Lyon, where we had dinner. There was a small carafe of wine on the table which was quickly consumed. We made several vain attempts to attract the attention of the waiter. Eventually, Colin grabbed the empty carafe, raised it above his head and uttered those immortal words: ‘Oy, garcon, we’ll be having un autre one of these, s’il vous plait.’

So, it’s amazing, isn’t it? Two groups of people separated by a strip of water and we can’t speak the same language.

The solution?
• More collaboration.
• More joint projects.
• Better communication.
• Better understanding of each other’s cultures.
• And, in this case, larger carafes!

Lesson 2
If you are a fledgling primary care diabetes organisation, and you don’t speak Diabetes UK, here are a few tips...
1. If people try to speak to you, or explain something, just ignore them.
2. Use Primary Care language, and stick to your guns, no matter what.
3. If you don’t get what you want, just shout.

In 1995, I was part of a group of individuals who set up Primary Care Diabetes UK. I was passionate, committed, but a little naïve. I believed that primary care management of diabetes was the way forward, and the only way forward. This brought me into conflict with the British Diabetic Association (now Diabetes UK). It caused all feeling and division. At this point I met Mary MacKinnon. I was already in awe of her, having used her diabetes book as a sort of bible. She had wisdom, people skills and a fair amount of cunning. She recognised my youthful enthusiasm, but taught me patience and respect, and
allowed our fledgling organisation to move forward. So it came as no surprise, when we were asked to select a named lecture for our group, that we chose Mary, and it is my great privilege to have been awarded this lecture (delivered at Diabetes UK, 13 March 2013).

The pendulum started to swing in our favour, perhaps because the powers that be realised that diabetes care could be delivered more cheaply in the primary care setting, but progressively it swung too far – diabetes units closing, consultant posts under threat, diabetes specialist nurses in the wilderness. This prompted my good friend, Neil Munro, to write an editorial in Practical Diabetes, drawing attention to the problem. It led to criticism in the primary care community, but it made me see sense.

So where are we now? We have the Primary Care Diabetes Society, the largest single interest primary care group in the world. We have ABCD, representing the consultant body. Due to strenuous efforts on both sides, we have a healthy dialogue – we talk to each other, but our computer systems do not, despite the fact that billions have been wasted on trying to find a solution. Perhaps we are victims of the ‘divide and rule’ philosophy which saw its origins in Thatcherism. She realised that a divided profession would be weaker and easier to regulate.

So it’s amazing, isn’t it? Two groups of people separated by an ideology, yet we can’t seem to speak the same language.

The solution?
- More collaboration.
- More joint conferences.
- Better communication.
- Better understanding of each other’s roles, pressures and agendas.

The last two objectives are best achieved by getting together to talk. I don’t mean over a commissioning table: I mean over a pint in the pub.

Lesson 3
If you treat people with diabetes and you don’t speak diabetes, here are a few tips…
1. If they try to speak to you, or explain something: just ignore them.
2. Use long medical words where possible, preferably Latin.
3. Ignore unnecessary interruptions and anecdotes.
4. If you don’t seem to be getting what you want, just shout.

In order to speak their language it would be helpful to know what to call them. This is the old chestnut about the use of the word ‘diabetic’. It is both a noun and an adjective but, over the years, I have been told not to call them ‘diabetics’ – they are ‘people with diabetes’ or ‘people living with diabetes’, or, as one extremist once told me, ‘people travelling the journey of diabetes’. So I decided to put it to the vote. I asked 100 consecutive people at the diabetes clinic how they would like to be known. The results:
- A diabetic 93
- A person with diabetes 6
- A person living with diabetes 1
- Travellers 0

But what started out as a light-hearted exercise, to once and for all silence the naysayers, revealed some interesting insights. One diabetic replied: ‘Yeah, diabetic, leper, whatever…’ Another, who had managed to ‘reverse’ his diabetes through a strict regimen of weight loss and exercise referred to himself as ‘a recovering diabetic’!

We use confusing language when talking with diabetics: isn’t it ridiculous that the word for low blood sugar, hypoglycaemia, sounds almost identical to the word for high blood sugar, hyperglycaemia, leading to potential misunderstanding and danger?

We use negative language when talking to diabetics. How often do we use the word ‘failure’? ‘Failure to attend’, ‘failure of oral therapies’, ‘failure to take medication’, ‘failure to reach the target’ (whose target?)? Ultimately, we talk of beta-cell failure, heart failure, renal failure. Perhaps we fail when we stop treating diabetics as individuals.

No wonder depression is commonly associated with diabetes. If you have diabetes, you are twice as likely to suffer from depression. Conversely, if you have depression you are twice as likely to develop diabetes, for a variety of reasons. And so we are encouraged to screen for depression. One of the suggested screening questions is: ‘During the past month, have you been bothered by feeling down, depressed or hopeless?’ (I sometimes have to remind myself that the question is intended for the patient, not the health care professional!) Another way of putting it would be:

‘You suffer from an incurable, progressive, complicated disease which has already shortened your life by 10 years. You have a very high chance of dying prematurely of cardiovascular disease, but before that time, you have the chance to develop serious and incapacitating complications, such as blindness, renal failure and amputation.’

‘So, tell me… do you ever feel down, depressed or hopeless?’

People who work in primary care know their patients and may find a better way to approach this, such as asking: ‘Has your husband got a job yet?’ or ‘How are you coping with your mother’s dementia?’

We used to talk about patient empowerment – we were doing so well; we used expressions like ‘therapeutic patient education’, ‘story based medicine’; we used open questions like ‘what are you ready to do?’ and ‘how can I help?’ And then along came QOF – when we stopped doing things for people with diabetes, and started doing things to them.

So it’s amazing, isn’t it? Two groups of people separated by a desk, yet we sometimes can’t speak the same language.

The solution?
- More collaboration – without tokenism.
- More joint projects, such as the excellent work undertaken by Diabetes UK.
- Better communication.
- Better understanding of each other’s roles, pressures and agendas.

And perhaps a good start is the recent EASD/ADA position statement, which advocates an individualised approach to glycaemic management based on a variety of indicators. I think it should be required reading for all health care professionals involved in diabetes management.
Lesson 4
If you are a member of the pharmaceutical industry, and you don’t speak diabetes, here are a few tips…
1. If people ask you to explain all your trial findings, just ignore them.
2. Use pharmacological language where possible, or failing that, marketing speak.
3. If you don’t get the sales you want, just shout (but only about the positive results).

Perhaps some of you have read ‘Bad Pharma’ by Ben Goldacre, in which he asserts that:
‘Drugs are tested by the people who manufacture them, in poorly designed trials, on hopelessly small numbers of weird, unrepresentative patients, and analysed using techniques which are flawed by design, in such a way that they exaggerate the benefits of treatment.’

This may be an extreme view, but the pharmaceutical industry can be accused of ‘sugaring the pill’ – an over-emphasis on sugar in the management of diabetes, peddling the mantra of ‘HbA1c: the lower the better’, when we know that this is not necessarily true, and of the lack of head-to-head studies. The remedy might include:
- Publication of all trial results.
- A clearer distinction between relative risk reduction and absolute risk reduction.
- No distortion of axes on promotional material.

So it’s amazing isn’t it? Two groups of people separated by a profit motive, yet we can’t speak the same language.

The solution?
- More collaboration.
- More joint initiatives, such as the rep academy set up by PCDS.
- Better communication.
- A better understanding of each other’s roles, pressures and agendas.

I don’t want representatives coming to see me about the latest wonder drug, who are unaware of what it means to be a general practitioner in the new NHS.

Lesson 5
If you are the government, or policy makers, and you don’t speak diabetes, here are a few tips…
1. If people try to speak to you, or explain something, just ignore them.
2. Use health service language where possible, especially if it hardly resembles English.
3. If you don’t get what you want, just shout.

Diabetes in the UK costs £1.5 million per hour. Only 7.8% of this is spent on diabetes drugs, whereas 65.8% is spent on inpatient care. These figures come from a report, published by the York Health Economic Consortium, and they prompted Baroness Young to remark: ‘The most shocking part of this report is the finding that almost four-fifths of NHS diabetes spending goes on treating complications that could have been prevented.’

This is hardly surprising, because successive governments, of whatever persuasion, have failed to grasp the notion that money invested in the early part of the disease will reap benefits in reduction of complications. The political life of a person with a long-term condition is peppered with changes of direction and short-term thinking. The current government is fond of making statements such as: ‘we believe that the new NHS structures will create opportunities for integration like we’ve never seen before.’

Integration? I will believe we have an integrated approach to health care when health policy is linked to education policy, transport policy, nutrition policy, town planning policy and health at work policy. It seems a distant prospect. Instead, we are confronted by the new NHS, where everything contains the letter Q: QOF, QP, QIPP, CQC, AQP.

The important Q, however, is the Diabetes Quality standards, published in 2011, but largely unread by health care professionals. They contain all the weapons we need to fight for better care for people with diabetes. Quality standard 5 states that: ‘people with diabetes agree with their health care professional to start, review and stop medications to lower blood glucose, blood pressure and blood lipids, in accordance with NICE guidance.’ Agree? That implies informed choice, individualisation of therapy and personal goals.

However, QP prevails on us to reduce admissions and unnecessary referrals. QIPP encourages us to increase our prescribing of sulphonylurea drugs and NPH insulin, while reducing home blood glucose monitoring. The conundrum is that following the QIPP agenda may lead to a requirement for more monitoring, to prevent more hypoglycaemia, which may lead to more hospital admissions and more outpatient referrals. I do not object to a set of quality standards which are aspirational and aim to support the delivery of high quality care, but I do object when the attainment of those standards is compromised by dictats which are obstructive and unhelpful, especially when they originate from the same source, namely the policy makers.

So, it’s amazing, isn’t it? Two groups of people separated by a stretch of water (the Thames), and we don’t seem able to speak the same language.

The solution?
- More collaboration.
- More joint working.
- Better communication.
- Better understanding of our roles, our pressures and their agenda.

This involves listening. The RCGP, the RCN and the BMA all opposed the health reforms, and they were all shouted down.

There are 350 million people with diabetes. Add to this number the carers, the families, the health care workforce, the pharmaceutical industry and the policy makers and it becomes imperative for us all to speak the same language. Otherwise, we risk building another tower of Babel.

I believe there has never been a more difficult and challenging time for health care professionals working in the field of diabetes. The new NHS, the increasing range of therapies, the ageing population, conflicting evidence: all pose challenges we must meet, but we can succeed in our endeavours – providing we can learn to talk to each other.

Bon chance!