Editorial

**The language of diabetes: the good, the bad and the ugly**

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Language is the essence of human communication. The very words we choose and the way we use them have meaning and influence those around us. If done well, communicating with and about people with diabetes can inspire, build confidence, and improve self-care and well-being; however, poor choices of words, phrases and body language can be de-motivating, stigmatising, and hurtful and undermine self-care efforts. Getting our language right is *not* a matter of political correctness – it affects the core of our interactions with and about people with diabetes.

Imagine this conversation, which could be taking place in your hospital:

Healthcare Professional 1: “Where’s the DKA?”

Healthcare Professional 2: “In cubicle 2, it’s Mr Smith.”

Healthcare Professional 1: “What, the diabetic who’s always here?”

Healthcare Professional 2: “Yes, the same.”

Healthcare Professional 1: “He’s so poorly controlled.”

Healthcare Professional 2: “Wasn’t he a subject in one of those recent insulin trials?”

Healthcare Professional 1: “Yeah, he was referred because he’d failed on human insulin, so they thought he might do better on an analogue. But he dropped out because he was non-compliant.”

Healthcare Professional 2: “I’m glad I’m not treating him.”

Healthcare Professional 1: “I know. He’s such a difficult patient.”

While this conversation is fictional, the phrases are frequently heard. So let’s analyse what was being said to understand how this conversation may have affected Mr Smith, his family, or indeed any other members of his healthcare team, if they overheard it.

While Mr Smith might have developed diabetic ketoacidosis, he is neither “a DKA” nor “a diabetic”. It is interesting to reflect which conditions have been turned into nouns to describe those who live with them. When you consider that no-one with haemorrhoids is called “a haemorrhoidic”, and no-one with cancer is known as “a cancic”, the ridiculous nature of the nomenclature becomes apparent. Labelling the person as their medical condition contributes to stigmatisation, and reinforces a tendency to attend to the condition and ignore the individual, whose identity is obscured by a set of pervasive generalisations (1). Even “diabetic patient” is worthy of further thought. While the majority of us are patients at some time in our lives, most people, including those with diabetes, do not live in this role for most of the time. The term “patient”, which originally meant “one who suffers”, defines the individual by their role and relationship with the healthcare system, namely as a passive recipient of healthcare services, or in need of treatment *by* a healthcare *provider*. Yet, the reality is quite different. People with diabetes live with, and actively manage, their condition every day, and this extends far beyond a specific relationship with a healthcare professional. It is commonly estimated that people with diabetes spend less than 6 hours (<0.001%) per year consulting with healthcare professionals, thus making routine use of the term “patient” inappropriate. Even when they are spending time in healthcare settings, it is counter-productive to define individuals with diabetes foremost by their condition (“a diabetic”) or by their role (“a patient”), as this diminishes them as a whole person, who has other priorities beyond their diabetes and who is an active agent in their self-care.

The description of Mr Smith as “poorly controlled” reveals several underlying assumptions and attitudes. Is Mr Smith really “poorly controlled” or does the clinician mean that *his diabetes* is “poorly controlled?” At best, this might be a slip of the tongue but, at worst, it may expose a deep-rooted attitude that Mr Smith should be more disciplined in his diabetes management, that he “lacks control”, is “out of control”, and should be “under control” or “controlled”. However, is it any more palatable to think that the clinician only meant to infer that Mr Smith’s diabetes (or his blood glucose) is “poorly controlled”? Although it is a step in the right direction, there are several problems with this language. Referring to “poor control” infers a moral judgment, and implies that Mr Smith has been “non-compliant” with the therapeutic regimen (2). When things are not going well, people with diabetes rarely benefit from this kind of criticism. It goes against theories of self-determination (action determined by intrinsic motivation) (3) and self-regulation (observing and reacting appropriately to one’s own efforts to manage a task) (4), which are predictive of successful self-care, weight loss and improved HbA1c (5,6). Second, true “control” is an enigma. The idea of controlling blood glucose (and diabetes itself) is appealing – few people like to be “out of control” and, indeed, many people with diabetes make great efforts every day to achieve personal control over their diabetes. However, there is no proven formula for managing diabetes and, in the real world, people need to use a high degree of judgment and experiential learning, independent of their healthcare professionals’ general guidance. Furthermore, suggesting that diabetes can be “controlled” dismisses various influences that may be beyond the individual’s personal control on any given day, such as illness, other medications, stress, hormones, delayed effects of physical activity, and weather. As one person with diabetes remarked during an education course, “*My* body hasn’t read *your* textbook”. Finally, judging Mr Smith’s high HbA1c level as “poor control” dismisses valid choices that he may have made about his diabetes management, such as strategically avoiding hypoglycaemia, to stay safe while driving or confident in his workplace.

Mr Smith appears to be struggling with his diabetes but is he really “failing on insulin” or is it his insulin that is failing him? This difference might seem subtle but it is important and likely to affect his self-esteem, motivation, and confidence to self-manage his diabetes. There have been many impressive advances in diabetes treatments and technologies in recent years, but none is perfect, and many add to the burden of living with diabetes (7). Persistent references to “failing” (e.g. “failing to lose weight”, “failing on oral meds”, “failing to achieve HbA1c targets”) leave people with diabetes feeling that healthcare professionals either do not appreciate the daily challenges of diabetes self-management or do not acknowledge the efforts they put into their self-care (8,9). Again, looking to other conditions, someone whose cancer does not respond to treatment is not said to “fail their chemotherapy”. Perhaps, this reflects a societal view that people with certain conditions are more deserving of empathy than others (10).

As the healthcare professionals in this scenario already believe they have evidence of Mr Smith’s previous “failure”, he is branded as “non-compliant” and they do not bother to look beyond this apparent character flaw. As one person with diabetes said to us recently, “It’s my pancreas that's ‘non-compliant’, not me!” Although labelling someone in this way may seem convenient, it is not effective as a means of improving diabetes management or outcomes. It may leave the healthcare professional feeling less motivated to support Mr Smith, as the study of expectancy effects demonstrates that humans display warmer attitudes towards those they consider more deserving (11). Labelling in this way also removes a valuable opportunity to ask relevant questions to explore why Mr Smith was not taking his medication as recommended. Does the regimen not suit him? Is he concerned about side effects? Is he confused by guidance that conflicts with advice from other healthcare professionals? Does he have sufficient diabetes self-management knowledge, skills and confidence? Has he become frustrated or ‘burnt out’ by the difficulties in achieving glycaemic targets? It seems unlikely that the healthcare professionals in this conversation will uncover the relevant issues while they perceive Mr Smith as “difficult”, uncooperative, and irresponsible, and believe that these are the reasons for his “poor control”. Yet Mr Smith was sufficiently motivated to volunteer to take part in a research study – as an active and willing “participant” and not a passive “subject”.

Deconstructing this seemingly simple conversation shows how language can undermine a therapeutic relationship, minimise opportunities to intervene constructively to improve health outcomes, and lead to frustration (and likely resentment) for both the person with diabetes and healthcare professional alike.

In the above conversation, the patriarchal view of diabetes management may be unconscious and even well-intentioned, but it does not reflect the reality of living and coping with diabetes, and it has several, albeit unintended, negative consequences. It is people with diabetes who have responsibility for their condition and who live with the effects of their decisions and actions. Whenever this is not acknowledged, an opportunity is lost to support the person with diabetes to live the best life they can.

So how might the conversation have gone with a little more empathy?

Healthcare Professional 1: “I understand you have just seen someone with DKA.”

Healthcare Professional 2: “Yes, Mr Smith is in cubicle 2.”

Healthcare Professional 1: “Oh, I know Mr Smith. He’s been here quite a few times this year. How awful for him.”

Healthcare Professional 2: “Yes, exactly.”

Healthcare Professional 1: “He is really struggling with his diabetes.”

Healthcare Professional 2: “Didn’t he take part in one of those insulin trials?”

Healthcare Professional 1: “Yeah, I can’t imagine how he managed all those hypos while he was using human insulin. So, he volunteered to try an analogue but it seems he is still having problems.”

Healthcare Professional 2: “So, that regimen isn’t working out well for him either?”

Healthcare Professional 1: “Type 1 diabetes is such a difficult condition to manage. I wonder what we can do today to support him.”

Time and time again, people with diabetes tell us they need “someone on my side” (12, 13). This does not mean a parent or teacher to scold them when their HbA1c is above the target range or to give them a “gold star” when it is within range. It means someone who “gets it”, who understands the difficulties and frustrations of managing diabetes on a daily basis and someone who is a coach “in their corner”, understanding and supporting their priorities, concerns and goals (14). When people with diabetes feel that their healthcare professional is not on their side, they are likely to stop confiding, to avoid judgment and negative reactions; some stop attending altogether. Indeed, while disengagement from healthcare can lead to high HbA1c, the opposite may also occur, whereby a high HbA1c is the precursor to disengagement due to fear of criticism (15). Healthcare professionals who openly discuss the challenges of living with diabetes are more likely to reach a shared understanding of the individual’s needs and will be able to work with the person to develop some collaborative goals and tailor self-management to better suit the individual’s life.

Position statements on language and person-centred communication have been published by Diabetes Australia (16) and the International Diabetes Federation (17), and a joint paper from the American Diabetes Association and American Association of Diabetes Educators on the use of language in diabetes care and education is due to be published in December 2017. NHS England has also recognised that a key component to improve care delivery is dependent on how healthcare professionals communicate with people with diabetes and thus, at a policy level, it is imperative that this issue is tackled to ensure there is appropriate guidance to support better diabetes care. Therefore, NHS England has established a working group in partnership with Diabetes UK, and including people with diabetes, academic and professional groups and independent organisations, to address how improving the use of language can lead to better clinical outcomes and quality of life for people with diabetes.

For several years, Diabetic Medicine has advocated the use of inclusive language because this issue is equally important in academic journals, not least because these fora are indicative of how we view people with diabetes, and the written word both shapes and reflects our attitudes and actions. This editorial is just one element of a collaborative and international initiative, gaining increasing momentum, to raise awareness of the impact of language on those living with diabetes, and on healthcare professionals supporting people with diabetes, and to offer an opportunity for us all to reflect upon, and improve, our use of language in diabetes care.

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