Dealing with diagnosis of diabetes

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Abstract
The diagnosis of diabetes is both a life-changing day for the person who receives it, and a challenging interaction for the time-pressed health professional who delivers it. This article reviews the evidence of factors that facilitate a more helpful diagnosis conversation, describes the importance of this initial conversation on long-term clinical outcomes, and offers suggestions drawn from psychological models on how to more effectively manage the diagnosis conversation.

‘Empathic willingness’ has been found to both assist the professional to feel less frustrated, and improve the patient’s experience and clinical outcomes in the long-term. ‘Empathic willingness’ can be taught and fostered by clinical psychologists (or their equivalents) yet are absent in the majority of settings in which people with diabetes are cared for.

While many health conditions allow us to treat the ‘body’, diabetes and other conditions that require self-management demand that we treat the ‘person’ – including their emotions. The link between the lack of structured time in the care of our patients to attend to their psychology/emotions and the poor clinical outcomes/high ‘did not attend’ rates that we see in our NHS diabetes services is discussed. Copyright © 2015 John Wiley & Sons.

Key words
diagnosis; emotions; psychology; empathy; empathic willingness

Patient quotation
‘I was told diabetes was without cure; I would need to have injections for the rest of my life, couldn’t eat what I wanted to and it would stop me following my dream of being a nurse. I hated it. It was the enemy. Now, four decades on, I’m 54 but with complications that leave me feeling old before my time. The doctors and nurses have meant well, but I’ve always felt like a bad diabetic. It was only when I saw a psychologist I started to feel differently. I realised I wasn’t “bad”; I just needed help understanding how to make diabetes part of me and part of my life. It took time. The doctors and nurses meant well, they were doing their job, but they didn’t have the time. Now my blood sugars are where they should be, but it’s too late for me.’

(Female with type 1 diabetes, age 54, quoted with permission.)

Introduction
The diagnosis of diabetes is a life-changing day for the person who receives it. It is also a challenging interaction for the time-pressed health professional who delivers it. This article reviews the evidence of factors that facilitate a more helpful diagnosis conversation, describes the importance of this initial conversation on long-term clinical outcomes, and offers suggestions drawn from psychological models on how to more effectively manage the diagnosis conversation. The focus of this article is on adults, and distinctions are deliberately not drawn between the type of diagnosis or setting in which it is delivered.

The challenge of diagnosis: the patient experience
Many studies into the effects of diagnosis have likened it to the grief process.1 There can be a mourning for the loss of the ‘perfect self’ who was unaffected by health problems. In the same way as grieving, dealing with diagnosis is therefore a process, not an event. The stages of grief, first described by Kübler-Ross2 in 1997 have often been cited as a useful framework for understanding the impact of diagnosis.

• Stage 1: Denial – ‘This can’t be happening.’
• Stage 2: Anger – ‘Why me?’ ‘It’s not fair.’ ‘How can this happen to me?’ ‘Who is to blame?’
• Stage 3: Bargaining – ‘I’d do anything to turn back time …’ ‘If only I
could have done things differently.‘ ‘Just let me be OK to see ‘ ‘Waiting for the diagnosis of diabetes to be confirmed is a stressful time, and many people struggle with this period of uncertainty. There are likely to be feelings of shock, fear, and anxiety, which can make it difficult to accept the diagnosis.

Stage 1: Denial
Denial functions as a buffer, or defence, to protect the individual from the full impact of the diagnosis. It allows the person to maintain a sense of normalcy and avoid facing the reality of the situation. Denial can be helpful in the short term, as it provides a coping mechanism, but it can also hinder the process of acceptance and adjustment.

Stage 2: Anger
Denial is replaced by feelings of anger, frustration, and resentment. The person may feel angry at the diagnosis, the way it was delivered, or the way they have been treated by healthcare professionals. Anger can be a natural response to the shock and stress of the diagnosis, but it can also hinder the process of acceptance.

Stage 3: Bargaining
Bargaining is the stage in which the person may hope to negotiate a better outcome or a delay in the diagnosis. They may envision a scenario where they could have done things differently. ‘Just let me be OK to see ‘

Stage 4: Depression
‘I’m so sad.’ ‘What’s the point?’ ‘I miss how life was before diabetes.’ Reaching the depression stage may appear grave, and certainly it is natural to want not to feel depressed. However, paradoxically, depression can actually be a sign of progress. It demonstrates that the person understands the certainty of their diagnosis, which is essential for resolution and progression.

Stage 5: Acceptance
‘It’s going to be OK.’ ‘I can take control and manage this.’ Acceptance is the final stage of the grief process; it signifies the person has come to terms with the diagnosis. Acceptance should not be mistaken for a happy stage. Rather, in acceptance, diabetes is allowed to be integrated with the person’s identity. Although it will often remain unwelcome, it can become a part of the person that can be cared for, rather than a stranger to be feared or fought.

By becoming aware of the feelings your patients have towards their diagnosis and recognising which stage of the process they are in, you can help them to manage the potential difficulties better.
The challenge of diagnosis: the physician experience

Polonsky et al. conducted an international study of the diagnosis of type 2 diabetes across 26 countries and reported that 60% of physicians described at least one significant challenge or frustration with most or all diagnosis conversations. Their research demonstrated that more frequent challenges/frustrations were associated with lower physician empathy scores. In the same study, Polonsky et al. found the impact of the diagnosis conversation was linked with ongoing clinical outcomes. The large majority of physicians (88%) reported that the conversation with patients at diagnosis has a substantial impact on their acceptance of disease and adherence to treatment.

They concluded that efforts to promote greater empathy in physician–patient interactions may contribute to a reduction in physicians’ frustration and challenges at diagnosis and, consequently, to better patient outcomes.

This points to an interesting question: if empathy improves the diagnosis conversations – which in turn improves clinical outcomes – can we ‘teach’ empathy?

According to Stein, a phenomenologist, empathy happens ‘to’ us – we find ourselves experiencing it, rather than directly causing it to happen. She concludes that this characteristic makes the act of empathy unteachable. Instead, promoting attitudes and behaviours such as self-awareness, non-judgemental positive regard and good listening skills are suggested as important in the development of clinicians who will demonstrate what she terms an ‘empathic willingness’. A number of researchers have shown that medical students lose some of their empathy as they learn science and detachment, and, once qualified, lose the remainder in the ‘wearness of overwork’. This makes for sombre reading.

The section that follows describes some conversational ‘sound bites’ that practitioners who are interested in increasing their empathic willingness can adapt to suit their own style. Some readers may find some of them a little basic or obvious; however, it is hoped that presenting a range of ideas may be helpful.

Increasing empathic responses to diagnosis

It is difficult to tell someone that they have diabetes. Once the facts have been delivered, it can be challenging to know what to say in response to an emotional reaction. Here are some suggestions that incorporate skills of empathy, to be adapted to suit personal style and language. Often, tone of voice can be key in fostering an empathic stance – a low volume, slightly slower speaking speed and eye contact are all essential.

• ‘This is hard to hear.’
• ‘This is a lot to take in.’
• ‘You have a right to feel [insert the emotion you see – upset/angry/con fused/uncertain etc] about this.’
• ‘It’s OK to feel the way you do.’
• ‘You have permission to feel upset/angry/scared about this.’
• ‘This news is a big life event and you will feel a whole range of feelings over the days to come.’
• ‘Just as the diagnosis of diabetes lets us know there are physical changes happening in your body, receiving the diagnosis also causes emotional changes, and these can show themselves through [insert whatever emotion you are seeing, e.g. tears/anger/feeling anxious/being low in mood]. This is natural.’
• ‘Although these feelings might not feel normal to you, they are a normal response to receiving this news.’

Person: ‘I’m angry that this has happened.’
Clinician: ‘Yes, you have a right to feel angry.’

Person: ‘I can’t believe this is happening.’
Clinician: ‘Yes it’s difficult to take in [pause]. In the same way as you have coped with other bad news, it is likely that you can and will cope with this.’

Person: ‘It’s not fair.’
Clinician: ‘Yes it’s not fair that your health isn’t the way you would like it to be. May I tell you what other people have treated often tell me? [pause]. They say that although it is hard at first, in time they can become to be grateful that it doesn’t cause them physical pain, and is treatable.’

Person: ‘I’m so sad.’
Clinician: ‘Yes, it IS sad thinking about this [pause]. When you have felt sad before, what has helped you? [if it is a struggle to think of ideas] May I tell you what has helped other people I have worked with? Some people tell me that although feeling some sadness is natural, talking about feelings can sometimes help, or doing something distracting to take your mind off it – watch a favourite film, read a book. Do any of those ideas sound possible for you?’

Person: ‘What’s the point of trying?’
Clinician: ‘Yes, it is really natural and common to wonder what the point of trying is. Many people I have worked with who feel this way go on to say there IS a point, and some even grow stronger as a person as a result. I understand that is little comfort now though.’

Person: ‘What have I done to myself? I’ve caused this myself.’
Clinician: ‘We all could make better decisions about our health, even us NHS professionals! Right now, I can help you take control to make different choices now and in the future.’

Person: ‘Diabetes is no big deal; there are worse things I could have.’
Clinician: ‘Yes you are right, there are worse things you could be experiencing. There are a number of health conditions that cannot be treated and managed in the way that diabetes can. It is important we are all grateful for the health we have. May I let you know why I think diabetes is a ‘big deal’? [wait for a ‘yes’ response]. We know that the more committed a person is towards taking care of their diabetes, the better their overall health outcomes tend to be. If you would like to, I would be pleased to help you.’

Person: ‘Why bother to care for myself? I’m going to die anyway.’
Clinician: ‘Yes you are quite right, we will all die of something eventually. I suppose what that is missing is the issue of ‘quality’ of life. I guess it is really up to you to decide whether taking care of yourself is worth it. We know that caring for your diabetes will help you ensure that the years you have will be as healthy as they can be.’
The link between diagnosis and improved clinical outcomes

There is a correlation between the diagnosis conversation and improved clinical outcomes.

Dietrich,\textsuperscript{10} investigated attitudes of people with type 2 diabetes and found that the reaction and attitude physicians displayed towards a patient at the point of diagnosis were critical in influencing that patient’s attitudes towards the perceived seriousness of the disease and consequently their adherence. An inadequate perception of the seriousness of diabetes was a factor contributing to a lack of adherence. Intuitively this makes sense: if the medical professional does not seem concerned, then for some people this will act as a model for their own lack of concern. A stance of clarity is important. Anecdotally, people often report that they are not clear whether or not they actually have a diagnosis of diabetes. They may have been told they have ‘borderline’ diabetes or be ‘tip ping into’ diabetes. Jarvis and Rubin\textsuperscript{11} point out that this is equivalent to telling a woman she has a ‘touch of pregnancy’. It is important we are clear in our communications.

Polonsky \textit{et al}.\textsuperscript{12} investigated both patients’ experiences when they were diagnosed with type 2 diabetes and their diabetes-related distress and self-management five years after diagnosis. Current diabetes distress was significantly lower among those who reported that they had been reassured at diagnosis that diabetes could be managed successfully, had been instilled with a sense of hope, and had developed a clearer action plan with their health care professional.

Although clinicians might be wary about giving too much information at diagnosis in case they overwhelm, patients generally find more information helpful, particularly if they are advised to consume the material at a pace that suits their individual needs.\textsuperscript{13} Reassurance that there is no rush to absorb the material, that they can work through it at a pace that suits them, is useful.

The key points for the health care professional, then, are:

- Foster an empathic response within diagnosis conversations.
- Communicate that diabetes is a serious condition, while reassuring the patient that diabetes can be managed successfully.
- Convey a sense of hope that they will learn to manage their condition with time.
- Give plenty of information about diabetes to take away. However, advise the person to use the material at their own pace.
- Develop a clear action plan for the next steps – their next appointment, referral to a patient education programme, signposting to Diabetes UK peer support service etc.

Learning lessons from other medical specialties

As health professionals, we are often concerned that our patients are not taking their diagnosis as seriously as we are. The evidence cited indicates that the way we deliver the news of the diagnosis may be unintentionally facilitating this stance. Although very different conditions, with very different cultural narratives surrounding them, we could perhaps learn lessons from oncology services. Diagnosis is delivered in a much more thought-through way, unrushed and usually with a family member present.\textsuperscript{14} There are perhaps parallels here with a diagnosis of type 1 delivered in a secondary care environment and diagnosis of type 2 within a brief routine primary care contact. Oncology professionals are expected to have training in communication skills, that includes ‘Breaking Bad News’.\textsuperscript{15} Does the evidence point towards diabetes services modelling the approach to diagnosis offered in oncology teams? Cultures both within and outside the NHS would need to evolve towards viewing a diagnosis of diabetes as an equally significant life event, and allowing the time, space and skill set to facilitate the diagnosis conversations within our services.

Conclusion

Every individual diagnosed with diabetes is unique, and therefore every diagnosis conversation will be a unique one. The literature highlights that an empathic stance within consultations both assists the professional to feel less frustrated, and improves the patient’s experience and clinical outcomes in the long term.

‘Empathic willingness’ can be taught and fostered, and although a professional group absent from the majority of diabetes care settings\textsuperscript{16} – despite being long called for in national service frameworks and commissioning guidelines\textsuperscript{17} – clinical psychologists (or their equivalents) are well placed within the multidisciplinary team to teach and model this empathic stance. In the same way as other members of the health care team, psychologists will vary in their levels of empathy, yet their training has equipped them with skills of self-awareness, non-judgemental positive regard and good listening skills, necessary foundations for developing an empathic willingness.

Diabetes is a medical condition; yet diagnosis brings with it an emotional response – for both individuals involved in the conversation. There is growing evidence that if we can create a space in our medical settings to focus on the emotional impact of diabetes, improved clinical outcomes can occur.\textsuperscript{18} While many health conditions allow us to treat the ‘body’, diabetes and other conditions that require self-management demand that we treat the ‘person’. Emotions are a key component of decision making that drives all of our health
decisions, patient and professional alike. Yet where in the multidisciplinary care of our patients are we systematically addressing their emotional needs? It is possible that it is not until we have services that do more than pay lip service to the value of psychology in the care of our patients that we will move beyond the widespread poor clinical outcomes and high ‘did not attend’ rates that we see in our NHS diabetes services. In the meantime, clinicians can continue to develop their skills in empathic willingness to enable those we care for to integrate diabetes into their identity and their lives; essential for health and wellbeing.

Suggested resources
- Diabetes UK peer support service: www.diabetes.org.uk/How_we_help/Peer-support/
- Social media: Twitter has an active diabetes community — use #diabetes and #doc (diabetes online community) to find those with diabetes engaged in conversations online.

References

Commentary
Helping the newly-diagnosed to adjust

Part of life’s rich pattern includes coping with the unexpected. Much of our learning is derived from early relationships and begins to prepare us to cope with surprises. Diabetes is a gate crasher. It is not invited; we don’t see it coming and rarely are we prepared to deal with it. Until it happens no-one knows for sure how they might react. It is the responsibility of each one of the health care team to recognise and support adjustment distress.

Receiving the diagnosis creates a range of emotions and thoughts. The way diagnosis is communicated, the information and support available at the time and the space to step back to reflect on what it means and how it feels, all contribute to the process of accepting and adjusting to living with the condition. Several studies have shown that the way people are managed when they are first diagnosed, including the adjustment distress consequent upon the diagnosis, can have an enduring effect on clinical outcomes in the long term.

Adjusting to a new diagnosis is often likened to a bereavement reaction and a specific model is described to interpret the process from shock to adjustment. It offers a framework for the health care team to recognise and process the distress.

The literature on psychological care suggests that it is often more important to ensure people feel understood rather than attempt to ‘fix’ or reduce what is a ‘normal’ human response to an unplanned change. It can be difficult to know what to say and how best to say it, and Jen Nash’s article in this issue offers examples of responses that are empathic and containing. However, the article focuses very much on the individual receiving the new diagnosis and the potential influence of the health care team. It is important not to forget that the individual functions in the context of a family, social group and colleagues, each of which will have not only their own reaction to the diagnosis but also a response to the individual receiving the diagnosis.

There is evidence to suggest that appropriate assessment soon after diagnosis can identify individuals who are likely to require more specialised psychological intervention. In the conclusion to her article, Jen Nash re-emphasises the need for appropriate skills training for non-psychological health care teams, and the continuing lack of access to diabetes specialist psychological treatments.

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References