Barry's story: a diabetes specialist nurse perspective

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ARTICLE POINTS

1 Healthcare professionals perceive the psychosocial impact of type 2 diabetes very differently to people who have diabetes.

2 Reactions to the diagnosis can be good indicators of how people with view and treat their diabetes.

3 Awareness and discussion of the possible need for insulin is important and should ideally be tackled soon after diagnosis.

4 The importance of diabetes nurses in providing education and support is highlighted by Barry's experiences

5 We need to use stories such as Barry's to help us reflect on the care we provide and encourage us t o listen more to people's fears, beliefs and experiences in order to provide the best care for individuals.

KEY WORDS
- **Type 2 diabetes**
- **Diagnosis**
- **Insulin initiation**
- **Treatment regimen**
- **Complications**
- **Lifestyle**

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Introduction

Healthcare professionals perceive the diagnosis and subsequent treatment of type 2 diabetes very differently to the people who have diabetes themselves. People's experiences and reactions at diagnosis can be good indicators of how they will view and treat their diabetes in future. Here, Jill Rodgers considers the experience of moving from oral hypoglycaemic agents to insulin therapy from a diabetes specialist nurse perspective, with all of the issues that may entail, and comments on Barry Malyed's experiences of the transition and how various aspects were managed. The importance of discussing insulin soon after diagnosis, input from the person with diabetes into choice of insulin regimen, and the role of the diabetes specialist nurse in providing support during this time are all discussed.

Barry's story about his 'diabetes journey' of 15 years, including his experiences since needing insulin treatment, provides us with some insight into being on the receiving end of diabetes care. It also provides an opportunity to reflect on what has made a difference to him in the care he has received.

Dealing with the diagnosis

Initially, he describes how he felt when he first became aware he had diabetes, feeling relief that it was 'treatable'. He also says he found it quite easy to accept the rigours of using his food intake, physical activity and prescribed medication to control his blood glucose levels. It can be easier for people to accept the diagnosis of diabetes when they have felt unwell for a while, as Barry had, although this is not true for everyone. It has been shown, however, that nurses and doctors perceive the psychosocial impact of type 2 diabetes to be significantly greater than people with diabetes do (Clark and Hampson, 2003), therefore we should not be surprised if people cope well. Conversely, Diabetes UK found that many people feel shocked and fearful at diagnosis, have limited understanding of the disease, and in this situation find it difficult to take in information (Diabetes UK, 2001). It is, therefore, important to explore how each individual views their diabetes in order to provide appropriate care and support.

Experiences and reactions to the diagnosis of diabetes can be good indicators of how people will view and treat their diabetes at a later date. For example, Barry's acceptance of his lifestyle changes at diagnosis is also reflected in his acceptance of insulin therapy. Conversely, people who find diabetes a struggle at diagnosis, seeing it as a burden or difficult to manage, may find it more difficult to accept treatment changes, which can add to their sense of guilt or failure.

Starting insulin

Barry describes his early awareness that insulin might be needed, alongside his concerns about the restrictions this would impose on his lifestyle. He later describes how, when the time came to start insulin, he was given 'very little time to consider or even contemplate' this prospect. It is sad that insulin was not discussed with Barry earlier in his diabetes journey, as this might have helped allay some of his concerns and

help Barry prepare for the likelihood of needing insulin. However, at the time he was diagnosed – around 1989 – initiating insulin in people with type 2 diabetes was less common than today. The publication of the UK Prospective Diabetes Study in 1998 raised awareness that insulin treatment is likely to be needed at some point for most people with type 2 diabetes (UKPDS, 1998), probably within six years of diagnosis (Williams and Pickup, 2004). More recently, financial incentives linked to tight glycaemic control for general practice populations are also likely to result in increased insulin use in type 2 diabetes (British Medical Association, 2003), and this is acknowledged by the National Institute for Clinical Excellence (NICE, 2002a).

One of the positive aspects of Barry's experience was that once the decision was made to start insulin, it was initiated immediately. The organisation and prior commitments of diabetes specialist nurses (DSNs) in many diabetes services does not permit this, but it makes sense that if a medication change has been decided upon, this should be acted upon as soon as possible. This helps to convey the importance of taking insulin to someone, whereas being told they need to wait a few weeks or months suggests that starting insulin is not all that important.

Choice of insulin regimen

Regarding the type of insulin used, Barry was initially started on twice-daily injections of 30/70 mixed insulin, but this soon caused hypoglycaemia, particularly at night. Barry describes how he needed to alternate between eating more to deal with hypoglycaemia and then requiring more insulin to deal with the resulting hyperglycaemia. He was eventually changed to four injections a day – glargine once a day, plus rapid-acting insulin with meals. This has enabled him to obtain better glycaemic control as well as being able to adjust his insulin dose in relation to meals, physical activity and his blood glucose level. He describes this insulin regimen as being 'ideal and reliable'.

The choice of which insulin regimens to use is predominantly made by the DSN (Thynne et al, 2003), and it has been shown that twice-daily mixed insulin is commonly used for people with type 2 diabetes (Rodgers, 1999; Jarvis et al, 2000). The advent of long-acting insulin analogues has been described as a favourable introduction to insulin therapy in type 2 diabetes (Owens and Griffiths, 2000), and NICE suggests it can be used in preference to twice-daily basal insulin injections (NICE, 2002b).

The Royal College of Nursing recommends that rather than using an insulin regimen preferred by the DSN, an empowerment approach should be adopted whereby people with type 2 diabetes should be involved as far as possible in selecting their own insulin regimen (Royal College of Nursing, 2004). This is not currently reflected in DSN practice, as shown above. It may be that we feel four injections a day, for example, is too arduous for someone, or that they will be unable to master adjusting their insulin doses. Barry describes the opposite, and says although it was inconvenient at first, he is now much more able to control his diabetes with a flexible regimen that has become part of his daily routine. Open discussion with people with diabetes about the options available can only result in closer matching of insulin regimens to people's lifestyles and preferences.

DSN support

Changing from one treatment to another can be traumatic for someone with diabetes, and this is particularly true when insulin is initiated. Barry describes the support he received from his diabetes nurse as being one of the key highlights of his experience. Some of the positive aspects he highlights are:

- careful explanation of what insulin treatment would involve;
- provision of written information;
- being visited at home for his first injection;
- including his wife in explanations;

PAGE POINTS

1 Discussing insulin with Barry earlier in his diabetes journey may have helped allay some of his concerns and prepare him for the likelihood of needing it.

2 A positive aspect of Barry's care was that insulin was initiated immediately when it was decided he needed it.

3 In practice, people with diabetes are not involved in selecting their insulin regimens, although it is recommended by the Royal College of Nursing.

4 Open discussions with people with diabetes about the options available can only result in closer matching of insulin regimens to people's lifestyles and preferences.

PAGE POINTS

1 It is important that however insulin is initiated, adequate support and information is provided, as is clear from Barry's positive experience.

2 It may be that (as in Barry's case) complications can manifest themselves as glycaemic control is tightened.

3 Stories like Barry's help us to reflect on the care we provide and should encourage us to listen more to people's beliefs, fears and experiences so we can enhance their success in living with diabetes.

- being available for advice during the working day.

The way that insulin is initiated varies greatly from one area to another depending on resources, geography, and organisation of services. In many areas primary care initiation is common. It is important that however insulin is initiated, adequate support and information is provided at this important time, and Barry's case amply describes the difference it made to him.

Insulin treatment and complications

Part of Barry's story describes how he developed neuropathy in his hands and feet, which he ascribes to starting insulin. It is a sad fact that long-term complications developing following a period of sub-optimal glycaemic control may coincide with the introduction of insulin, rather than insulin being a causative factor. We can all recall people who have mistakenly made this link, for example, 'My mother started insulin and then lost her eyesight' or 'My uncle had a heart attack after he started insulin'.

It may be that complications (in Barry's case, neuropathy) can manifest themselves as glycaemic control is tightened, but long-term improvement in blood glucose levels is likely to reduce the development of complications. We need to explore what beliefs people hold around insulin, glycaemic control and complications, in order to help them understand their treatment.

Conclusion

This article has focused on a variety of aspects of insulin initiation, as highlighted by Barry's story. How the diagnosis of diabetes impacts on an individual, how insulin is discussed and initiated, how we choose an insulin regimen, what support we provide, and how we discuss the complications can all impact either positively or negatively on the person at the receiving end of our care. Stories like this help us to reflect on the care we provide, and should encourage us to listen more to people's fears, beliefs and experiences in order to provide our care in the context of their lives. We cannot assume anything about people's beliefs – we need to explore each individual's story so that we can enhance the potential of them living successfully with diabetes ■

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