Understanding barriers to commencing injectable therapy in people with type 2 diabetes

Joanne Given, Deirdre McCay, Alyson Hill, Maurice O’Kane, Vivien Coates

The transition from oral to injectable agents is often delayed in type 2 diabetes by both people with diabetes and their healthcare providers. This study aimed to assess the experiences of people with type 2 diabetes in order to identify improvements that could be made in the transition to injectable therapy. Both positive and negative experiences were identified and a number of practice recommendations have been made, which may improve the experience of transition for all individuals. This will continue to be an important issue for the health service due to the increasing number of people being diagnosed with type 2 diabetes and the emphasis on “treating to target”.

Type 2 diabetes is often initially treated with lifestyle intervention, followed by the sequential introduction of oral hypoglycaemic agents. However, because of the progressive nature of the condition and the need to attain glycaemic targets, it may be necessary to initiate injection therapy in the form of either insulin or a glucagon-like peptide (GLP-1) analogue in a significant proportion of individuals (Abdul-Ghani et al, 2013).

This transition from oral to injectable agents is often delayed by both people with diabetes and their clinicians (Siminerio, 2006; Peyrot et al, 2010). In one UK study, it took 1.8 years before 25% of people in whom oral therapy had failed were started on insulin. It was a further 5 years before 50% of individuals were taking insulin, even in the presence of diabetes-related complications (Rubino et al, 2007). This delay exposes the individual to prolonged periods of hyperglycaemia and increased risk of complications (UKPDS [UK Prospective Diabetes Study] Group, 1998). It can also result in the individual becoming frustrated with their efforts to control their diabetes, leading to reduced motivation, less active self-care and treatment pessimism (Peyrot et al, 2010).

This “clinical inertia” or reluctance to start insulin therapy is often known as psychological insulin resistance (Peyrot et al, 2010). Its contributing factors are diverse and multi-factorial, including practical, psychosocial and behavioural issues (Bogatean and Hâncu, 2004). These include an unwillingness to accept the need for such a step-up in treatment, fear of injecting, the perceived complexity of treatment and the potential for side-effects and complications.

Insulin use is also associated with a social stigma and a sense of failure in terms of self-management (Bogatean and Hâncu, 2004; Brod et al, 2009; Peyrot et al, 2010). As a result, the initiation of injectable therapy can be one of the most difficult and important choices that individuals with diabetes have to make (Brod et al, 2009).
Aim
The current study aimed to assess the experiences of people with type 2 diabetes in order to identify improvements that could be made in the transition to injectable therapy.

Method
This work was undertaken at the diabetes service at Altnaglevin Hospital (Western Health and Social Care Trust). The hospital diabetes clinic serves a catchment population of around 120,000 and comprises a multidisciplinary team (dietitians, doctors, nurses, podiatrists and psychologists). The majority of people participated in shared-care arrangements with hospital and primary-care-based teams. As this work arose from a local service evaluation, ethics committee approval was not required. However, all participation was voluntary. Confidentiality and anonymity were observed during all phases of data collection and reporting.

A focus group approach, where information is generated through group discussions (Morgan, 1998), was adopted. This provides the opportunity for participants to reflect on and react to the opinions of others. It also has the potential to identify a wide range of opinions, as well as underlying conflicts, which would have otherwise remained unknown (Parahoo, 2006).

Adults with type 2 diabetes who had been commenced on an injectable agent (insulin or a GLP-1 analogue) within the previous year were identified from the hospital diabetes database. All had been individually initiated on their injectable therapy, rather than in a group setting. Out of the 91 potential participants identified, 22 had commenced insulin therapy and 69 an injectable GLP-1 analogue. To allow for an anticipated non-response rate of 30%, 18 individuals were invited to participate and were selected using a purposive sampling process (Polit and Beck, 2010) based on age, gender and type of injectable therapy. All participants attended the same focus

Box 1. Open and closed questions used in the interviews.

- How did you feel when you were told you needed an injectable treatment?
- What process did you go through at the diabetes clinic?
- Do you feel you received enough nursing support?
- Do you feel you received enough dietetic support?
- Did your diet and lifestyle change?
- How do you feel about injecting?
- Do you have any concerns about future changes in treatment?
- Would you have liked more education and support?
- How would you like information delivered to you?
group regardless of the type of injectable therapy or the length of time since transition.

The interview schedule included both open and closed questions (Box 1, previous page) and probes were used to encourage responses (Bowling, 2009). The focus group discussion was recorded digitally, with permission, and field notes were taken by the moderator (DMcC). The interview was then transcribed verbatim and analysed using thematic content analysis (Krueger and Casey, 2009). Initially, DMcC read the transcript a number of times to familiarise herself with the data. Interpretive comments and likely themes were then noted on the transcript and this information was brought together, along with key statements, to describe the themes. An independent analysis of the data was conducted by JG who reviewed and verified the results and major themes.

### Results

Twelve individuals participated in the focus group (Table 1), which lasted 1½ hours. A number of themes arose around their experiences of commencing injectable therapy and how it could be improved. These themes were: the emotional response, communication, knowledge provision and support from healthcare providers.

#### The emotional response

Many participants described feeling shocked when they were told they would have to start an injectable therapy. While some were unaware that injectable therapy was even a treatment option in type 2 diabetes, others had not realised that the step-up in treatment was so imminent.

“It was a shock. Because I thought I was doing great because I had lost 2 stone last year.”

“Starting insulin was a shock….I thought I had more time.”

Many participants described feelings of fear and anxiety on commencing injectable therapy. This related to the practical aspects of diabetes management, such as self-injecting, avoiding hypoglycaemia, maintaining satisfactory glycaemia, but also the impact on their lifestyle, such as their ability to drive, go on holiday or socialise.

“When I did go on it, I got very scared.”

“I would sit and worry about things.”

Many of these emotional responses resulted from perceived problems with communication and knowledge provision, which emerged as separate themes.

#### Communication

A perceived failure to discuss the likely future need for injectable therapy, a lack of time to explain the need for the treatment change and an assumption that individuals would readily accept the step-up in treatment left some people feeling excluded from the decision-making process.

“The pancreas had failed so they decided then to put me on insulin, [they] just say you’re on it, have a word with the dietitian, have a word with the diabetic nurse.”

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<th>Injectable therapy</th>
<th>Individual</th>
<th>Duration of type 2 diabetes (years)</th>
<th>HbA1c (mmol/mol)</th>
<th>BMI (kg/m²)</th>
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Table 1. Sample demographics.

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Participants felt that “some preparation time would be good” so that they could feel they were “edging towards” injectable therapy. Indeed, when they had been warned and the rationale explained, individuals were much more accepting of the change in treatment.

“I had been told it might be a possibility and why, and I’d been told each time I came to the clinic. I think I didn’t panic because I had been told more gradually.”

Knowledge provision
When initially started on injectable therapy, a lack of clear and concise information could lead to “information overload” for some participants:

“Many people are telling you many different things [and] it’s very difficult to take it all in.”

Gaps in knowledge, particularly surrounding blood glucose monitoring and diet, made diabetes self-management difficult.

“Well, when I was 15 to 17 [mmol/L], that would alarm me, they said it was high, but some people tell me 4 [mmol/L] is high.”

“It wasn’t until lately that I found out that, that the more starchy or stodgy breads, the worse they were for me.”

It was suggested that providing more information before the change to an injectable therapy would have meant that individuals “might not have worried so much” and “could’ve been doing things right from the start”. Written information was seen as helpful:

“It’s good to have the leaflets to back up what they tell you in clinic, sometimes you don’t take it all in at the time.”

Support from health care providers
The majority of participants talked positively about the clinical care and support they received from healthcare professionals, particularly the diabetes specialist nurses. If they encountered problems with their injectable therapy, it was easy to get advice over the telephone or to have an urgent appointment scheduled:

“I would have no problem lifting the phone talking to [a nurse] and saying ‘I’m … this is my situation, what can you do?’”

“There were days I’d come up and say I don’t feel at all well, hitting high spots and I was more or less taken straight into a consultant.”

Participants also felt supported in their decision making:

“I was handed [an injectable agent]… couldn’t cope with that at all and felt confident enough that I could stop it knowing that no one was going to have a go at me.”

However, there were occasions when individuals felt that they had received conflicting messages and this resulted in unnecessary anxiety:

“I wasn’t too happy with them at all, it was like, ‘you’re very close to insulin’, so I got myself mentally prepared on the next visit to ‘I’m going to get insulin this time’… So I went into the doctor and the doctor says no your bloods are perfect, your kidneys is working well, this is working but I’m prepared now, and it didn’t happen.”

This may have arisen due to a changed clinical situation. It is important that there is effective communication between the patient and all members of the clinical team so that the patient understands the time-line leading to injectable therapy and the factors that will determine when exactly the change might occur.

Discussion
Consistent with previous work (Bogatean and Hâncu, 2004; Noh et al, 2005; Peyrot et al, 2005; Wood, 2005) the majority of participants in this study described a negative emotional response when they were informed that they would need to commence an injectable therapy. In particular, a perceived lack of effective
communication and knowledge provision ahead of the transition to injectable therapy left individuals feeling shocked, fearful and anxious.

Care guidelines have consistently advocated that those with type 2 diabetes are informed from the time of diagnosis that it is a progressive condition that will often require insulin therapy (NICE, 2009). Although guidelines are in place, it is unclear to what extent these are adhered to, or to what extent individuals with diabetes fully understand the progressive nature of their condition and the possibility of requiring injectable therapy. Communication research has shown that dissonance between what healthcare professionals think they have covered with patients, compared with patients' perceptions of a consultation is not uncommon (Parkin and Skinner, 2003). Communication needs to be improved to minimise these discrepancies.

Current healthcare policy in Northern Ireland (Department of Health, Social Services and Public Safety, 2011) and elsewhere reinforces the need for empowered people who can self-manage long-term conditions, yet the impression from these results, for some people at least, was one of relative disempowerment:

"... so they decided then to put me on insulin, just say 'you're on it, have a word with the dietitian …""

A systematic review of the literature relating to communication between healthcare professionals and patients regarding medicines reported that:

"Patients rarely initiate medication topics and can take a passive role when discussing medicines with health care practitioners."

(Stevenson et al, 2004).

It is essential to advance practice and encourage empowered and knowledgeable individuals to take an active part in discussions about their treatment progression. The benefits of a more pro-active patient approach include greater patient engagement and satisfaction (Stevenson et al, 2004).

People with diabetes may interact over time with different members of the diabetes team in both a hospital and community setting. Although it is important that a consistent message is given by different team members, this can be difficult to maintain over the longer term, particularly as the individual's clinical situation, and as a result their care plan, may change rapidly (Haggerty et al, 2003).

In order to help overcome potential barriers to starting injectable therapy, appropriate education to increase knowledge, promote shared decision making and reduce psychological stress is required. While there are education programmes available for the introduction of insulin and GLP-1 analogues, such as X-PERT Insulin (©X-PERT Health) and the Injectable Therapies Toolkit (©The DESMOND Collaborative), these relate largely to the administration of therapy and the management of the condition through injections. They do not prepare people for the eventual transition from oral agents to injectable therapy.

The findings of this study suggest that some of the anxiety and stress associated with a decision to move to injectable therapy might be mitigated by a specific "pre-injectable" education programme delivered some time before it becomes necessary. This programme might address the rationale for injectable therapy, what factors might indicate the need for a move to injectable therapy, an overview of how such treatments might be delivered and individualised, and to address patient concerns and fears. While the rate of progression of type 2 diabetes will vary between individuals, such an education programme might be offered when people move to three separate oral anti-diabetic agents, or when there is an expectation by the clinical team that injectable therapy will be required within 12 months. It is recognised that there will always be some individuals where the decision to move to an injectable agent, particularly insulin, will have to be taken immediately with often little time for preparation.

The recommendations arising from this study are:

- Review how information about treatment progression is delivered, including an
Understanding barriers to commencing injectable therapy in people with type 2 diabetes

“The findings of this study suggest that some of the anxiety and stress associated with a decision to move to injectable therapy might be mitigated by a specific ‘pre-injectable’ education programme.”

Assessment of the extent to which this information has been understood.

- Develop a specific “pre-injectable” education programme to be offered to individuals where it is considered that injectable therapy will be needed within 12 months.

A weakness of the current study was that the patient group was self-selected and therefore the experiences described may not be representative of the entire diabetes population starting injectable therapy. Furthermore, the number of participants was small and limited to one service.

**Conclusion**

The present study found that a majority of participants had a negative emotional reaction to the decision to start injectable therapy. It is proposed that an educational programme be developed to prepare people for progression to injectable therapy, enhance participation in decision making and to minimise any adverse emotional impact. This might help overcome clinician and patient barriers to commencing injectable therapy, and result in an improved experience for people with diabetes and better glycaemic control.

**Acknowledgment**

This study was carried out with financial support from the Western Health & Social Care Trust and the University of Ulster Discretionary Fund.


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**Authors**

Joanne Given is a Research Associate, University of Ulster; Deirdre McCay is a Diabetes Specialist Dietitian, Western Health and Social Care Trust; Alyson Hill is a Lecturer in Dietetics, University of Ulster; Maurice O’Kane is a Consultant Chemical Pathologist, Western Health and Social Care Trust; Vivien Coates is Assistant Director of Nursing Research/Professor of Nursing Research, University of Ulster and Western Health and Social Care Trust.