Short Report

Continuous subcutaneous insulin infusion in Type 1 diabetes: patient experiences of ‘living with a machine’

L. Todres, S. Keen and D. Kerr*

School of Health and Social Care, Bournemouth University and *Bournemouth Diabetes and Endocrine Centre and Centre of Postgraduate Medical Research and Education, School of Health and Social Care, Bournemouth, UK

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Abstract

Aims The aims of this study were to provide in-depth insight into the changes that may be experienced by patients embarking on continuous subcutaneous insulin infusion and to answer the research question, what is it like to live with an insulin pump?

Methods An in-depth, qualitative, multiple interview study of individuals with Type 1 diabetes using continuous subcutaneous insulin infusion in a secondary care setting in the south of England. Four patients (two male, two female) across the age range and with varied experience of pump use, were recruited from a specialist diabetes centre.

Results Switching from multiple injection therapy to insulin pump therapy presents challenges in the short term. Over a longer period, use of this technology is associated with a significant improvement in quality of life for the users and also a change in the relationship between the patient and their specialist healthcare provider.

Conclusions Insulin pump therapy has additional qualitative benefits beyond improvements in glycaemic control and reducing the risk of hypoglycaemia for people with Type 1 diabetes.


Keywords continuous subcutaneous insulin infusion, patient experience, qualitative methods, Type 1 diabetes

Introduction

People living with Type 1 diabetes face a difficult task. They need to avoid the risk of developing long-term complications by keeping blood glucose levels as close to normal as possible, but at the same time avoid unheralded hypoglycaemia. Continuous subcutaneous insulin infusion is associated with a lower risk of hypoglycaemia and improved glycaemic control [1–3] and, based on this and other evidence [4–8], the UK National Institute for Health and Clinical Excellence has recently revised the guidance on its use, with the expectation that more individuals with Type 1 diabetes should be offered this form of insulin delivery [9]. With appropriate selection, training and review of patients considering continuous subcutaneous insulin infusion, there are suggestions that it also enhances quality of life [1,3,4,6,10,11], although this is in no way a consistent finding [5,12].

Qualitative research in the UK [5] and the USA [13–16] has begun to highlight the substantial life-changing benefits of continuous subcutaneous insulin infusion. It may not be surprising that such a targeted treatment option produces improvements in suitable patients’ quality of life. This short report is focused on aspects of quality of life improvements that occur with continuous subcutaneous insulin infusion, in order to provide practitioners with an understanding of the possible quality of life benefits, as well as some of the challenges.

Subjects and methods

This study has concentrated on a small number of individuals in order to elucidate the changes experienced by patients embarking on continuous subcutaneous insulin infusion. A qualitative, descriptive phenomenological [17], research design has been used to distil essential themes from four in-depth patient-generated stories.
There were two phases to data collection [18]:
(i) phase 1 (breadth): an in-depth biographic narrative interview that pursued an open-ended exploration of the informant’s story of living with diabetes and embarking on insulin pump therapy;
(ii) phase 2 (depth): a follow-up interview (after 3 months), which focused on seven themes that emerged from the earlier interviews.

This short report is focused on the phase 2 interviews, in which LT and SK asked informants to describe in detail their experiences in relation to a particular theme. We used a purposive sampling strategy to choose four patients, with varied experience of pump use, from a specialist diabetes centre (Table 1) (LREC reference 07/H0201/136).

All interviews were digitally recorded and subsequently transcribed. A rigorous five-stage analytic procedure was pursued by LT and SK [19] (Table 2), independently verified by DK.

Results

This section presents our qualitative insight into the six themes we identified after the initial round of open-ended biographic interviews (Table 3). An overview of each theme is linked to an elaboration of sub-themes and, where appropriate, how these sub-themes occur in individual cases.

Challenges

For these patients, there was variation in the kinds of adjustment that occurred, which appeared to depend on differences in personality and personal history, including:
(i) adjusting to an increased sense of accountability for the self-management of their condition and the emotional implications of this sense of accountability. These included fear of disapproval by health professionals and feelings about their worthiness to receive this ‘cutting edge’ treatment;
(ii) learning to trust and accept the benefits of the new treatment regime involved a process of ‘letting go’ of some previous self-management routines, and also letting go of the fears that had previously built up about consequences that would now no longer occur;
(iii) adjusting to others’ perceived views and interactions about pump therapy—such adjustments involved working out strategies about how to manage interactions with others and also thoughts about how the pump could be better designed;
(iv) an initial adjustment to the thought of ‘being on a machine for 24 hours a day’, but quickly followed by a realization of the benefits from continuous subcutaneous insulin infusion, which made this concern redundant.

Changes in relationships with health professionals

The patients found that the changes in their relationships with their health professionals were significant. There were two important features that characterized these changes.
(i) A movement towards a more collaborative relationship with their health professionals in which their role became more active in learning about their condition and making refined adjustments in living relative to the management of their diabetes.
(ii) A strong feeling that this relationship had proven itself credible over time in producing real and helpful changes in controlling the diabetes and in the consequent improvements in quality of life.

These changes in relationships resulted in the patients seeing a shift in their own identities whereby they felt more enabled by both the technology and the relationship with their health professionals to take more meaningful responsibility and control for their condition.

Realizing greater control

For the patients, a greater sense of control first came with the stabilization of their blood glucose levels over time. Such consistency and technical control was aided by regular blood testing and precise carbohydrate counting, as well as by the patients being more sensitive to the internal sensations associated with blood sugar fluctuations.

Increased technical control over blood glucose levels through pump technology also led to the patients gaining a noticeable increase in personal control over meaningful everyday routines and social activities, experienced as a more carefree existence. The patients felt less ‘dictated to’ by their

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<th>Table 1 Characteristics of insulin pump users</th>
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<td>Gender</td>
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<tr>
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diabetes and were less wedded to the need for regular routines than before.

Learning

For these patients, there appeared to be two important types of learning that followed their commencement of continuous subcutaneous insulin infusion:

(i) they learnt specifically about the uniqueness and complexity of their own diabetic pattern and how to make effective adjustments for the productive management of their diabetes;

(ii) they learnt a greater degree of self-acceptance about what it means to 'be a person with diabetes'. Such self-acceptance arose through greater self-knowledge about their own unique diabetic pattern and of how to adjust to it. This learning also resulted in a greater willingness to take more personal responsibility for the self-management of their condition.

The process by which such learning took place involved an ongoing cycle of active experimentation and feedback. This helped the patients to further refine the management of their condition and led to greater self-confidence and further motivation to take active control over and personal responsibility for their diabetes.

Expanding activities

The patients found that there were two types of activity that were significantly different compared with before they began using pump technology.

(i) Engaging in social situations became more spontaneous, in that there was a greater willingness to take a risk in unpredictable situations that may have previously required careful planning and provoked concern about maintaining routine.

(ii) Engaging in physical and/or organizational tasks could be pursued in a less preoccupied way. The patients had greater confidence to extend themselves, knowing that the ramifications of their diabetic condition would not be as extreme as before pump technology and could be more easily remedied.

The patients using the pump technology were able to experience greater freedom by being less dependent on planning, thus increasing their sense of flexibility to respond to less flexible situations. Expanding into these two areas of activity appears to result in a less preoccupied and a more carefree identity.

'Significant others'

For those close to the patients in their personal lives, there was a clear recognition of the benefits of diabetic pump technology and a sense of gratefulness for these changes. Two kinds of benefits were highlighted from the point of view of the significant other:

(i) an appreciation of the improved health of the patient;  
(ii) an appreciation of the increased flexibility in living that diabetes pump technology affords the patient.

Conclusions

The findings describe specific ways in which these patients experienced significant improvements in their quality of life since embarking on continuous subcutaneous insulin infusion. Ironically, in these cases, living with a machine has resulted in a greater humanization of their care [20]. These cases also show a greater control over symptoms and insulin levels [5], a greater sense of personal empowerment in terms of self-knowledge and self-care [14], a greater sense of self-acceptance and a greater sense of active collaboration and partnership between the patients and their professional carers. Living with this machine has enabled them to become ‘expert patients’ [21] and has resulted in better self-management strategies and
lifestyle opportunities. These insights may be helpful to professionals when counselling prospective users of the technology about its quality of life benefits when it is working well.

Study limitations
This study was about ‘quality of life’ benefits of living with insulin pump technology when it was working well. This study also concentrated on providing in-depth insights from the lives of just four people. Further studies are needed to focus on the more comparative questions about the generalizability of these quality of life benefits among different population groups, and the more clinically focused questions about indications and contraindications for prescribing insulin pump technology. A further large-scale quantitative study could fruitfully gain knowledge about the number and range of patients who experience these benefits and the challenges, and some insight into the circumstances surrounding those who do not benefit. In conclusion, the benefit of this study is its hope-giving message, which could encourage patients (and indeed health professionals) for whom the therapy is positively indicated.

Competing interests
LT and SK have nothing to declare. DK has received honoraria for participating in educational meetings sponsored by the manufacturers of insulin pumps.

Acknowledgements
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