Insulin pump therapy is perceived as liberating, but to many it can imply a sense of the diabetes made visible

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Summary

This study describes how adults with type 1 diabetes experience the transition from multiple daily injections (MDI) to continuous subcutaneous insulin infusion (CSII or 'insulin pump'). The study is based on interviews in focus groups, with 11 persons with type 1 diabetes who had had CSII for at least one year, which were analysed using qualitative content analysis. The analysis resulted in three categories: life and health; involvement of others; and technology dependence. Participants' experiences are summarised in the theme 'CSII is perceived as liberating, but also implies a sense of the diabetes made visible'. The transition resulted in changed life and health with greater freedom and flexibility, particularly in meal situations. The participants felt that their blood glucose was easier to control. Those around them reacted with curiosity, but some participants felt compelled to tell others that they had diabetes since the pump could be seen or heard. The participants found that coping with CSII in daily life was easier and more comfortable than they had expected. However, having to constantly be prepared for technical failure was experienced as cumbersome. All participants indicated that they were satisfied with their treatment and recommended it to others. Transition to CSII may be experienced as liberating, but might also imply a sense of the diabetes made visible. The results can be used in clinical practice, when advising about CSII. Being aware of both positive and negative experiences with CSII can contribute to better care for those already being treated with CSII.

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Key words

diabetes mellitus type 1; insulin infusion system; quality of life; treatment satisfaction; qualitative research

Introduction

In Sweden 15–30% of adults with type 1 diabetes are treated with CSII.[1] Studies comparing CSII and MDI have shown that CSII can improve HbA1c, decrease blood glucose variability and reduce the number of hypoglycaemic events.[2–8] Some studies measuring health-related quality of life and treatment satisfaction have shown a benefit from CSII, while others have failed to demonstrate any differences.[9] It is difficult to compare outcomes, however, as different instruments are used.[6]

There are few qualitative studies on how people with diabetes experience the transition to CSII.[10–13] Results from these studies show that people with CSII experience many benefits that the treatment offers, such as increased flexibility, freedom, and better blood sugar levels. The studies also indicate that CSII has its disadvantages: the pump can be seen under clothes, there can be problems at the injection site, and pump failure. However, the benefits appear to outweigh the disadvantages.

Aim

The aim of this study was to describe how patients with type 1 diabetes experience the transition from MDI to CSII.

Method

Design

Qualitative study based on focus group interviews. The interviews were analysed using qualitative content analysis.[14]

Participants

Inclusion criteria were adults with type 1 diabetes being treated with CSII for one to two-and- a-half years. Exclusion criteria were patients with type 2 diabetes and those who did not speak Swedish. Focus group interviews were conducted in February 2012. Information letters were sent to 22 people with type 1 diabetes who had received an insulin pump at the Endocrinology Department of Karolinska University Hospital in Solna from 1 September 2009 to

15 December 2010. The study enrolled 11 subjects with type 1 diabetes: six men and five women. The average age was 46 years (range 25–74 years); mean HbA1c was 65 mmol/mol (range 43–84); diabetes duration 4–46 years; four patients had retinopathy, while there was absence of nephropathy in all patients. Those who did not participate in the study did not differ significantly from the participants with regards to their backgrounds.

Procedure

The 11 participants were divided into two focus groups containing both men and women. The interviews were tape-recorded and lasted 90 minutes each. An interview guide was used to ensure that the aim of the study was followed.

Initially, all participants were asked to explain why they had switched from MDI to CSII. Further questions addressed patient experience in switching treatment, the impact of insulin pump therapy on patient lives, patient experiences of using insulin pumps on a daily basis, practicalities of wearing the device, as well as the level of support received from healthcare professionals. Participants were also encouraged to talk about other peoples' reactions. Finally, participants were asked how satisfied they were with CSII and whether they would recommend it to others.

Analysis

The interviews were analysed using qualitative content analysis, as described by Graneheim and Lundman.[14] The recorded material was transcribed verbatim and the text was read through several times to get a sense of the overall feedback. Then words, sentences and phrases were identified and grouped into meaning units, which were then connected to each other based on content and context. The process continued with condensation: the condensed meaning units were coded and grouped into subcategories, which were then merged into categories. The categories represented the manifest content of the text. Finally, one theme emerged as an interpretation of the text as a whole, bringing out its latent content.

Ethical consideration

The study was approved by the regional ethical review board in Stockholm on 14 December 2011 (Dnr 2011/1870-31/). Information letters were sent to all participants and written informed consent was obtained from them.

Findings

The participants' reasons for switching from MDI to CSII were high HbA1c, high blood glucose variability and hypoglycaemia. All respondents indicated that they were satisfied with the transition to CSII and that they would recommend it to others.

Content analysis resulted in ten subcategories that were merged into three categories: life and health; involvement of others; and technology dependence. The participants' experiences are summarised in the theme 'Insulin pump therapy is perceived as liberating, but also implies a sense of the diabetes made visible.'

Life and health

The interviews revealed that the transition to CSII had led to changes in daily life compared with MDI. The participants had gained increased meal flexibility, felt they had better control over their blood glucose levels, and felt less anxious and fearful. Several participants indicated that they had trouble keeping a good blood sugar balance in connection with physical activities.

CSII allows for more flexible meals

Participants felt that the transition to CSII had given them better quality of life with regard to food and meals, and indicated greater meal flexibility.

With MDI, the participants usually ate at fixed times, which led to a loss in hunger sensation, while with the pump, they could eat more flexibly and had regained the feeling of hunger.

'Now you eat when you're hungry; that was a feeling that I had lost' (male 29 years).

They also experienced relief at not having to keep track of injections, especially when eating with others.

CSII can be an obstacle during exercise

Several participants stated that it had become more difficult to exercise after the transition. It was difficult to balance food, exercise and insulin. They felt that their blood sugar was frequently too low after exercise.

'I haven't quite got it right; I reduce the dose several hours before I exercise, and eat. However, I often get low when I exercise' (female 27 years).

One participant had CSII in his teens, and when he exercised intensively he could not have the pump on, which resulted in difficulties controlling his glucose levels. Now he does not exercise as intensely, and it works well to exercise with the insulin pump.

'When I exercise I have it on the whole time, except when I go swimming, then I disconnect it. It works a lot better now' (male 25 years).

CSII implies better blood glucose and easier control

Several felt that the transition had made them feel better; they felt more alert and their blood glucose was lower and more even.

'I have a much better quality of life. I feel a lot better' (male 25 years).

With the pump it was easier to decrease high blood glucose levels with extra bolus doses.
The frequency of hypoglycaemia had decreased, and they expressed that it had become easier to feel the symptoms and treat them.
'Because it's much easier to treat the hypos, and like you, I feel the hypos better now than I did before' (female 62 years).

CSII reduces treatment concerns

Transition to CSII had led to a feeling of not being as restricted and limited as with MDI. Some experienced a reduction in uncertainty and concern about forgetting a dose, as it was easy to see the pump's history of when the last bolus dose was taken.
'It is a relief to have the pump, it definitely is. Now I can actually go back and look at when I did it' (female 74 years).
Some experienced less fear of nocturnal hypoglycaemia.
'Sometimes I think back to that time and how scared I was to go to bed at night, and how scared I was when my family were away' (female 45 years).

Involvement of others

Reactions from close relatives were mostly positive, although initially they could be frightened or disturbed. The interviews also revealed examples where the insulin pump made the diabetes more visible. Participants felt compelled to tell others they had diabetes because the pump could be seen, or heard if its alarm went off.

CSII implies that ones closest relatives may initially be frightened or disturbed

Relatives could be disturbed if the insulin pump's alarm sounded during the night. Some female participants said they had experienced reactions from those they lived with, who had initially shown fear and used a cautious approach in the context of intimate encounters. However, this had gradually disappeared.
'My boyfriend is pretty scared of needles and hospitals. He was a bit hesitant, you know, a little cautious with me' (female 27 years).
However, the discussions revealed that children and grandchildren had not reacted negatively.
'The second reaction has only been from my grandchildren who really want to push up what I should have [insulin] and show them how it works' (female 74 years).

CSII increases curiosity and interest from those around them

One participant expressed that there are many misconceptions from those in one s surroundings about what diabetes is. Sometimes it could be completely wrong, such as wanting to give insulin during a hypoglycaemic event.
'I sometimes get into discussions with people who say that if I have low blood sugar, I probably just need a shot of insulin' (male 25 years).
The discussions revealed that several participants, however, felt that the people around them were often interested and wanted to know about how an insulin pump works. The participants felt they had to tell more people about the diabetes now that they had the pump, than they had done previously with MDI.
'I get a lot more questions that make me tell people that I'm diabetic' (female 45 years).

Technology dependence

Most participants felt that managing the pump was not a problem; it was easy and convenient. All participants agreed that the actual transition from MDI had been easy, whereas being prepared for technical failure and planning changes could be perceived as difficult. The participants were continuously linked to technology and mostly relied on it, but high blood glucose levels could make them worried. The pump had become a natural part of the body for the participants. However, female participants expressed problems with clothing and felt a sense of never being completely naked.

CSII means being in need of continuous technology support

Before switching from MDI, many thought it would be more difficult to manage CSII. Some participants felt there was too much information in the beginning, and that everything could not be set, and called for a 'refresher course' in order to build on their knowledge. In the discussions, several participants said it was easy and convenient to use CSII.

All participants felt they received not only the help and support they needed from health professionals, but also help with technical issues from the pump manufacturers' customer support.
'It just gets better and better; the transition from syringes to pump was painless. I think it is much easier to have the pump than all those syringes' (male 25 years).

'Well, I have no problem dealing with the insulin pump in everyday life; you fill it and replace the cartridges' (male 64 years).

Constant preparedness for technical failure

What many experienced as difficult was that they always have to bring additional accessories, such as batteries, tubes, needles and insulin, in case something happens.
'You always have to be prepared and have your bag full of things' (female 45 years).
Changing reservoirs, tubes and needles takes time, and some also indicated that it is stressful to make these changes at work.

'You do not always have time and I do not bring stuff for changing' (female 27 years).

A few participants expressed that it was also necessary to order equipment at the pharmacy in good time, because the pharmacy did not keep pump accessories in stock.

CSII means needing to be continuously linked to technology

Participants expressed that they had initially thought it would be difficult to always be connected to the pump, but it turned out not to be as they had feared; the insulin pump came to feel like a part of their body. They relied on it, but expressed that they were worried there could be something wrong with the pump if their blood glucose increased. Some other technical aspects could be experienced negatively: the needle could hurt and blood glucose was affected if the needle was in the wrong place, had been in for too long, or if the tubes were caught and subsequently torn out.

CSII and the insulin pump will eventually become a natural part of the body

Most participants felt that the insulin pump had come to be like part of their body. However, female participants expressed concerns about wearing it with appropriate clothes.

'As a woman, I like tight skirts and dresses, I can't wear that anymore. I have to choose clothes based on the pump' (female 43 years).

Some women expressed that they never felt naked. Although the insulin pump was disconnected, the needle remained there as a visible reminder.

'You are never completely naked, even when you disconnect it, you have that little thing' (female 27 years).

Discussion

Participants perceived insulin pump therapy as a sense of relief with greater flexibility in daily life, and felt that their glycemic control had improved. Some mentioned that it had become more difficult to exercise after the transition to CSII, as their blood sugar frequently became too low. Participants felt that those around them had mostly positive reactions, such as curiosity and a willingness to help, but that they had to tell others they had diabetes when the pump s alarm sounded, and when people asked questions about it. Being linked to technology and always being forced to carry an insulin pump were experienced as easier than they had expected before the switch. However, it could also be perceived negatively to never feel completely naked, and always having to carry pump supplies and insulin pens since the technology could fail. Although the participants experienced some disadvantages of insulin pump therapy, the benefits outweighed them.

Life and health

Several results emerging from the content analyses overlap the results shown in other studies with children, teenagers and adults. The results in these studies indicate that insulin pump users experience greater flexibility regarding meals and lifestyle habits, an increased sense of freedom, reduced diabetes-related anxiety, and less concern about having nocturnal hypoglycaemia.[4,5,15] The current study confirms these results and participants in our study also felt that their blood sugar levels had become lower and smoother with fewer hypoglycaemic events, as several clinical studies and meta-analysis of randomised controlled trials have shown.[3,6–8,16] In qualitative studies with adults as well, greater freedom and flexibility in lifestyle habits[10–12] and improved quality of life[13] have been demonstrated.

What distinguished this study from other studies was the participants' experience that it had become more difficult to exercise after switching to the insulin pump due to hypoglycaemia. One reason for this can be inadequate education from healthcare providers.

Involvement of others

Reactions from the participants' closest relatives were mostly positive. Both family members and those around the participants reacted with curiosity and interest. Other studies have shown similar results, with an improvement in social relations.[5,10] Co-workers' willingness to help could sometimes aggravate the situation, for example, when they suggested taking insulin in cases of hypoglycaemia.

Technology dependence

Always having insulin with you when wearing an insulin pump was a benefit. However, several participants agreed that it is troublesome to always have to bring along additional equipment. Female participants felt it was sometimes difficult to know how to wear the pump so that it would not be visible through clothes. A telephone interview study by Barnard and Skinner showed the same negative effects: that the insulin pump was visible, and could sometimes cause skin problems, such as bleeding, fat deposits and marks.[10] In a focus group interview by Ritholz *et al*, women expressed more negative feelings due to the fact that the insulin pump could be seen under clothes.[12] The participants were divided into different groups depending on HbA1c levels; those with high HbA1c described more negative feelings about wearing an insulin pump. A qualitative interview study by Todres *et al* indicates that it is a challenge to always be connected to a device, but that this

is outweighed by the benefits of insulin pump therapy.[13] All participants in the current study felt that they got the help and support they needed from health professionals, unlike in the study by Barnard and Skinner,[10] in which participants felt they did not receive adequate help with pump failure from medical staff.

Several studies show that insulin pump users experienced greater treatment satisfaction and recommended insulin pump therapy to others.[3,4,6,8,10,15,16] In the current study, all participants indicated that they were satisfied with their treatment and that they would recommend the insulin pump to others. Some quantitative studies did not show any significant differences in treatment satisfaction.[2,9]

Study limitations

The method in this study is qualitative content analysis. The analyses can be done at both a manifest and a latent level. The manifest level answers the question 'what', and the latent level 'how'.[14] In this study, we have mainly used the manifest level. The results might have been richer if we had analysed the interviews more deeply on a latent level. However, we found these results important and worth presenting.

The disadvantage of interviews in groups may be that there is a risk that one participant takes over the discussion, while others do not dare express themselves, especially if they have differing opinions. In this study, an interview guide was used and the participants had to answer and discuss the issues one by one in a circle, and the others could interpose with their own opinion or supplementary questions.

A weakness of this study is that only half of those asked wanted to participate maybe because the interviews were to be conducted in groups; if the authors had chosen individual interviews, it may have been easier to recruit participants and the outcome might have been different.

Conclusion

Transition to insulin pump therapy can be seen as liberating, but can also imply a sense of the diabetes made visible. All participants experienced increased treatment satisfaction.

The results show that the transition from MDI to CSSI has both advantages and disadvantages. For example, it can be easier to eat more flexibly and have better blood glucose control, while the disadvantages include being linked continuously to technical equipment that might fail, and that the insulin pump can been seen under ones clothes. The results can be used by physicians and diabetes specialist nurses when planning education for persons with type 1 diabetes, who are going to begin insulin pump therapy. Being aware of both positive and negative experiences of CSII can contribute to better care for those already being treated with CSII.

KEY POINTS

- The transition to insulin pump therapy resulted in greater freedom and flexibility, especially in meal situations
- The participants felt that their blood glucose was easier to control and they had better health
- All participants were satisfied with their treatment
- Disadvantage of insulin pump therapy was that the diabetes became more visible

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