A hermeneutic phenomenological study of why adults with type 1 diabetes choose to discontinue CSII

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Summary

This qualitative study was designed to examine why people with type 1 diabetes choose to discontinue continuous subcutaneous insulin infusion (CSII). The sample consisted of five adult participants with type 1 diabetes who had already taken the decision to discontinue CSII. Data were collected using audio taped, semi-structured interviews. Tapes were transcribed and analysed using a thematic analysis. Three themes emerged: (1) the challenges of wearing the pump, (2) lack of control over the pump, body and health, and (3) comparing expectations versus reality. Results are of relevance to people with diabetes, those professionals referring, commissioning and providing a service, and manufacturers.

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Key words

CSII; discontinuing; type 1 diabetes

Introduction

Continuous subcutaneous insulin infusion (CSII) was introduced in the early 1970s and evolved from the desire to develop a delivery system that simulates normal pancreatic function.[1] The separate determination of the basal and bolus functions allows flexibility in timing and the use of short-acting insulin analogues to provide coverage of a dawn phenomenon,[2] ease sick-day management[3] and match nutrient absorption more physiologically, reducing the risk of hypoglycaemia and severe hypoglycaemia.[4] CSII has the potential to improve glycaemic control[5] and improve quality of life with greater control, flexibility, dietary freedom, family effects, convenience and independence.[6,7] Despite these benefits, 2–4% of patients discontinue CSII after a short period of time.[7] Understanding why people choose to discontinue is important as it could be argued that time and finance are wasted, the risks of complications increased and discontinuation may contribute to feelings of failure and inability to manage their diabetes appropriately.

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Literature review

A literature search was undertaken using the 'My Athens' search engine, electronic databases and journals using the key words: 'continuous subcutaneous insulin infusion', 'CSII', and 'insulin pumps'. Articles not yet processed or indexed were included in the search. Only full articles and not abstracts were used. After reading articles, the reference lists from comprehensive review articles were used to identify additional original research publications. When reviewing the research further consideration was needed to identify if modern insulin pumps and insulin analogues were used. No research was identified from the introduction of analogue insulins (1996) and smaller insulin pumps.

Methodology

Qualitative research methodology, in the form of hermeneutic phenomenology was chosen. The researcher (MH), who works as a diabetes specialist nurse although not at the pump centre that recruited the participants, kept a reflective journal throughout the study recording her stance as a person living with type 1 diabetes on CSII. The journal was used to record impressions, interviews and interpretations about the meaning and methodology. Access to the diabetes population was sought from the diabetologist following ethical approval from Dorset Research Ethics Committee. Permission to interview patients was given but without access to patient notes; this was to ensure that the research remained impartial. Semi-structured interviews allowed participants to express their experiences and feelings. Participants came to the interview knowing they had to describe the reason or reasons why they chose to discontinue CSII.

Sample

Purposeful sampling was used to identify male and female participants with type 1 diabetes who had chosen to discontinue CSII from a single site in the South of England. Permission for six participants was given but only five (out of 12 who had discontinued pump therapy at this centre) could be identified as meeting the research criteria; they were all invited and agreed to take part. No exclusion based on gender or race was made, but all the participants were white British. The researcher gave a brief explanation of the research and a patient information leaflet was sent to interested participants. The sample therefore consisted of five participants, selected by the diabetes team as being suitable and willing to participate.

Data collection and analysis

Interviews were audio taped and transcribed. The transcriptions were then checked by participants to ensure faithful representation. Two research assistants were invited to generate category systems that were checked by the principal investigator. The transcripts were used as raw data and used in analysis. The method included open coding; this required line-by-line scrutiny of the data to identify key words or short phrases, which were arranged under the appropriate heading and sub-headings. One copy of each transcript remained intact, so that coded sections could be checked in context against the original transcript. Elitist bias was guarded against by giving participants numbers to ensure one participant was not over represented or recognised by others. In keeping with hermeneutic phenomenology, participants read through their interviews and three chose to participate in a second interview. This process promotes trust and rapport, confirming the accuracy of the transcribed data, tentative findings and formulated themes.

Results

Challenges of wearing the pump

The inconvenience of wearing the pump. Participants expressed reasons for coming off the pump in terms of 'the inconvenience of wearing the pump'.

'I know initially I did come off purely because of the inconvenience of wearing it' (001F).

'…every time I turned over in bed I had to make sure that the pad was still sticking to me because it would come loose…' (002M).

'My work is physical; filling up the shelves there was too much twisting and turning and bending' (002M).

'I did find it a heavy big thing' (003F).

Time consuming. Programming the pump was time consuming and participants preferred to take control of the decision-making process.

'I had the bolus … [calculator] one and even that I found programming everything in, although it was great what it did again, it took a lot of time and I just sort of wanted to get on with things' (003F).

Participant 003F was unaware which type of batteries were needed for pump therapy or that she could get her batteries on the NHS from her pump company with her other consumables. She was buying her batteries, which caused her problems, as they did not last for many days. She did not seek help from the pump team, and this contributed towards her decision to discontinue.

Visibility (unable to hide the pump). All three of the female participants described the difficulty of trying to hide the pump particularly in the summer.

'I think it was more noticeable in the nice … in the hot weather because you always had … a pair of shorts on, you always had that [the pump] and like a huge mobile phone or if you wanted to put it in your bra it stuck out. Or if you had it carried out around your waist it could be seen underneath the T-shirt' (001F).

'I just found it very bulky to wear with anything really you know if you wear a dress you know they say if you are big busted stick it down your bra, but I am not big busted and to wear a dress and especially if they are clinging in the summer what do you do with the pump, there isn't anywhere to put it because the lump would just show through' (004F).

'It didn't matter what it looked like, but it was putting it on the outside' (003F).

Previous studies found visibility and the concealment of the pump were reported as a negative theme in CSII users,[7] and women were more concerned than men about body image and social acceptance with CSII.[8]

Managing on the beach. All three female participants described the difficulty of managing the pump on the beach. They were concerned that sand would damage the pump and worried about the length of time they felt they could safely disconnect from the pump to enjoy the beach.

'Swimming of course, if I was on the beach you had to clock watch because I did used to worry about getting sand on it and then if you were in and out of the water all the time they advise not to be without the pump for more than two hours' (003F).

Discomfort and skin irritations. The needle was found to be thick, long and hurt at insertion with some participants continuing to be aware of the needle or cannula causing an intermittent feeling of discomfort.

'…if the needle wasn't so harsh to be inserted in your stomach I don't [think] there would be a problem because when I was on it the needle was quite thick and it was quite long and it did hurt and it doesn't matter what anyone says; it does hurt when you insert it and you do get very sore and uncomfortable, and at times you can actually feel it in you all the time which isn't pleasant if you are connected up with it 24 hours a day' (004F).

Despite various solutions being offered, the skin bruised or was red, itchy and sore. One participant stated skin irritation as his only reason for discontinuing the pump, while other participants described this as one of the reasons.

'...I was getting a red rash in the area where the needle and plaster was and it took a long while to get rid of it. It reminded me of a sweat rash. I tried putting from the chemist the false type of skin ... but it still didn't make any difference … that was the only reason I came off it … I was forever itching … it is just too irritating to continue with it' (005M).

Previous studies found discomfort; irritation or infection at the injection site was the most common reason for discontinuing.[9] Dermatological problems were described as a factor associated with discontinuing.[9,10]

Emerging theme: intimacy issues. *'I think that is a problem "oh blimey be careful, can't disconnect you" I think the partners are more aware of disconnecting you … I don't think it is the embarrassment side of it, I think it is just an inconvenience if you turn over you have to bring your pump over with you and you have got the tube and you come disconnected what if you know you nudge it with your arm or put your arm under the lead you pull yourself out so you have got to connect yourself up again well … that is going to put any woman off, it is going to put any man off'* (004F).

Lack of control over the pump, body and health

Technical failures. Two participants had pump failure and the pump was changed immediately by the hospital team.

Falling off and disconnecting. The pump would unexpectedly become disconnected from its attachment place, which often disconnected the cannula or caused leakage. The pumps are unable to alert the users to a disconnection at the cannula site, which allows the insulin to leak rather than be absorbed. This can go undetected and lead to high glucose and has the potential for diabetic ketoacidosis. This led to a constant concern that the cannula might come loose.

'I love my gardening, sweating out in the garden in the summer, doing a bit of digging, it would come off and more than once it would just fall to the ground. What is that? Oh, hang on it has fallen off again, so another insertion another sticky pad; when you are sweating it won't stick properly anyway' (002M).

Previous research has noted participants were anxious on matters of CSII failure,[11] key negative themes of CSII as breakdown,[7] and the inconvenience of catheter or needle occlusion.[12] In all of these studies, patients remained on CSII.

Doubting the technology. The technical challenges faced by the participants included not using all of the functions on the pump, doubting the pump, not trusting the pump, not trusting self, self-ability and, for one participant, not being able to do so for psychological reasons.

'Sometimes you … with the pump you wonder if it is working properly' (001F).

'I was having problems at night time, the alarm would go off, there would be a blockage in the tube or my insulin would run out even though I would always check the amount of insulin that was in the pump before I went to bed' (004F).

Participant 002M did not trust the pump technology to work out his insulin requirements because of a previous frightening experience. He explains he had a fear of night-time hypoglycaemia following an unpleasant incident. He wanted to keep his bedtime glucose high so as to avoid this happening again. He therefore knew the technology could not account for this experience and so he could not rely on it to produce the results he wanted.

'I am paranoid about an episode that happened 18 years ago where I went hypo at night and I was always cheating on the … [bolus calculator]. I was taking extra carbohydrates at night, which pushed up my sugar levels … I just haven't got the confidence to use it properly. It is there and it can work but you have got to be of the right physical disposition and mental aptitude to use it properly' (002M).

Emerging theme: lack of control over body and health. *'At night I can't help think that if the buttons pressed or … even in the day if you knock it or something goes in or too much, you haven't got full control over what you are putting in your body really so that was part of it as well'* (003F).

'I wanted to be the one measuring up how much insulin I was going to inject rather than pushing a few buttons the … [bolus calculator] comes into action and says you need this much and you just press go, it didn't feel as if you were having a proper input into your own health; you were but it didn't feel like it' (002M).

Expectations versus reality

This theme is divided between participants' and health care professionals' (HCPs') expectations.

Participants' expectations. Participant 003F considered her reasons for giving up and felt that she would have found a way to cope with the pump if it helped her glucose – that is, the pump failed to meet her expectations of improved glucose so the challenges outweighed the benefits. Participant 001F echoed this sentiment.

'I think it is a combination really it all leads onto each other when you really look at them it shouldn't really [be] the challenges of wearing a pump if it is helping your blood sugars I guess you would just find a way of dealing with it but just at the time when I was using it, it just wasn't happening for me so I think it is just a combination of all of it' (003F).

'In the way, simple. Really I think it is in the way and the fact that it didn't meet up to the expectations that I perhaps thought it would in overall control' (001F).

Previous research reported participants decided to give up CSII as it did not improve their control.[13]

Comparing the pump with previous insulin regimen. Participants were noted to be constantly making comparisons and assessing life on a pump with their previous treatment on injections, which led to decision making.

'I feel it is an easier option to have the injections rather than have this carrying the pump all the time' (001F).

'I think really injections is the best option but if they can make the pump smaller but maybe not so small but try and make it thinner I think it would be so much better' (004F).

The freedom given by the pump was not necessarily a positive freedom.

'I think initially the problem with the pump is … you feel the sense of freedom … I actually did put on weight because … I became more carefree' (001F).

HCPs' expectations. The National Institute for Health and Clinical Excellence (2008) gives clear expectation to HCPs that the therapy should only be continued if there are sustained improvements to HbA_{1c} results or if there is a sustained decrease in hypoglycaemic episodes.[14] Three participants at their diabetes reviews experienced an opportunity to consider if they should stay on their pump; for 001F and 002M this gave the opportunity to make a final decision immediately, while 003F continued CSII until her next appointment.

Emerging theme: life pressures. Two participants described the reality of life's pressures being a part of their decision to discontinue CSII.

'I think that a lot of things were happening at the time. Like I was … getting divorced … it was … after I first had … my marriage split up I started uni and that was going a bit iffy. I was in a flat on my own and I was trying to sell it, there was just loads of different bits and pieces going on so … my mind was elsewhere other than concentrating on this new thing I have' (003F).

Discussion of findings

The research has highlighted the demands of type 1 diabetes self-management made upon people living with the condition and the need for improved training and further support with many aspects of CSII to be readily available. The women in this study would have particularly benefited from help to solve the problems of wearing and hiding the pump and emotional support with the difficulties they described. Clear direction on protecting the pump and how to maintain glucose control while on the beach is needed. For those who suffer from skin problems (from the tape at the site of the cannula or needle), more understanding of the causes and possible solutions are needed to support those who would otherwise prefer to continue pump therapy.

For those who doubt the technology, an opportunity to explore their knowledge, beliefs and confidence in their ability to learn to use CSII is essential. In order for individuals to manage their expectations, manufacturers are required to advertise the pump as a tool, which needs constant training until mastered. When designing pumps, manufacturers need to consider that by increasing the complexity of the functions this may become a burden to some of their customers.

In the service where I (MH) work we place individuals with type 1 diabetes at the heart of our thinking, providing empathy, knowledge and holistic support rather than focusing on the disease or technology. Our clinical psychologist with dedicated time within the pump service is proving essential during assessment, education sessions and support groups to help people continue CSII. As the qualitative study by Ritholz *et al*[8] showed, it is common for individuals to have a strong emotional reaction to the suggestion of pump therapy. Sometimes they need individual or group support to emotionally adjust to pump therapy and we use our clinical psychologist to facilitate this work. Interestingly, Ritholz *et al*[8] found that individuals who had an emotional reaction similar to that when they were diagnosed with diabetes gained better glycaemic control once on a pump than those who did not. This may indicate that being in touch with feelings evoked by pump therapy is important to adjustment and continuation of treatment. Ritholz *et al*[8] noted similar issues to this study around body image concern, and high expectations of pump therapy sometimes in conflict with individuals' expectations of how much participation in self-care pump therapy involves. All of these issues are explicitly addressed through our pump support group.

Intimacy issues are not fully described or understood from this study, and further research is required to explore these issues. In addition, the sample only contained white British people which may limit its generalisability to other UK settings.

Conclusion

This research has shown that hermeneutic phenomenology, as a research method, is effective in understanding the lived experience about why people with type 1 diabetes choose to discontinue insulin pump therapy. It opens up discussion for health care professionals on training and support needs for individuals regarding CSII and proposes further research be carried out.

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Conflict of interest statement

There are no conflicts of interest.

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