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Qualitative study into quality of life issues surrounding insulin pump use in Type 1 diabetes

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Abstract

Currently, there is a need for qualitative research about how insulin pump therapy changes quality of life, which is significant to people with type 1 diabetes. This study aimed to elicit the experiences of current insulin pump users in order to discover the therapy's benefits, downsides and effect on their quality of life. A qualitative approach was taken in order to reveal subjective experiences. This research will inform future research and assist with policy and guideline development by health care providers about pump therapy.

Participants were briefly interviewed by telephone about their experiences of living with an insulin pump. Four questions were asked. These covered the benefits of pump use, effects on quality of life, whether participants experienced downsides to using a pump and any other issues participants wished to raise.

In all, 80 insulin pump users participated in the study. All 80 reported experiencing benefits; insulin pump use had improved their quality of life. Key positive themes emerging from the data included greater control (45), flexibility (33), freedom (28), family effects (seven), convenience (seven) and independence (five). Key drawbacks emerging from the data included visibility– device (25), breakdown (17), visibility– skin (five) and cost (three).

Participants overwhelmingly reported experiencing benefits and improvements in their quality of life associated with insulin pump use. These pump users remain on pump therapy by choice, so the benefits clearly outweigh the downsides. However, further work needs to determine if these downsides contribute to explaining why 2–4% of pump users discontinue pump use after a short period of time, or whether this is a result of other factors. Copyright © 2007 John Wiley & Sons.

Keywords

Qualitative, Study, into, Quality, Life, Issues, Surrounding, Insulin, Pump, Use, Type, Diabetes

Disciplines

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Qualitative study into quality of life issues surrounding insulin pump use in type 1 diabetes

Katharine Barnard and T Chas Skinner

Keywords: Insulin pump, continuous subcutaneous insulin infusion, CSII, quality of life, well-being, health status, health outcome

Abstract

Introduction: Currently, there is a need for qualitative research about how insulin pump therapy changes quality of life, which is significant to people with type 1 diabetes. This study aimed to elicit the experiences of current insulin pump users in order to discover the therapy's benefits, downsides and effect on their quality of life. A qualitative approach was taken in order to reveal subjective experiences. This research will inform future research and assist with policy and guideline development by health care providers about pump therapy.

Methods: Participants were briefly interviewed by telephone about their experiences of living with an insulin pump. Four questions were asked. These covered the benefits of pump use, effects on quality of life, whether participants experienced downsides to using a pump and any other issues participants wished to raise.

Results: In all, 80 insulin pump users participated in the study. All 80 reported experiencing benefits; insulin pump use had improved their quality of life. Key positive themes emerging from the data included greater control (45), flexibility (33), freedom (28), family effects (seven), convenience (seven) and independence (five). Key drawbacks emerging from the data included visibility— device (25), breakdown (17), visibility— skin (five) and cost (three). **Conclusions**: Participants overwhelmingly reported experiencing benefits and improvements in their quality of life associated with insulin pump use. These pump users remain on pump therapy by choice, so the benefits clearly outweigh the downsides. However, further work needs to determine if these downsides contribute to explaining why 2–4% of pump users discontinue pump use after a short period of time, or whether this is a result of other factors

1. INTRODUCTION

There are numerous benefits to using continuous subcutaneous insulin infusion (CSII) according to published literature. These include improvements in glycaemic control, reductions in glucose fluctuations and reduced rates of severe hypoglycaemia.1 Many people have also reported that using CSII has resulted in improvements in their quality of life,2–5 but this is by no means a consistent finding.6–8

Previous studies have assumed that a quantitative measure of quality of life will pick up issues relevant to people moving to insulin pump therapy. However, this does not appear to be the case. The most widely used measure, the Diabetes Quality of Life (DQOL),9 was developed for the Diabetes Control and Complications Trial (DCCT),10where it appeared to lack sensitivity regarding issues surrounding hypoglycaemia. Yet fear of hypoglycaemia is known to be a major concern for people with type 1 diabetes.11 Further criticisms of the DQOL are well publicised and include a lack of sensitivity for fear of hypoglycaemia. Also, DQOL is not sensitive enough to pick up differences when comparing interventions, such as pump therapy *vs* multiple daily insulin injections.12 Some studies used measures like SF36. This is actually a measure of functional health status, not of quality of life. Other studies have used non-validated measures, such as the ITR-QOL (insulin therapy related QOL), giving unreliable results. Thus, the key question is how to appropriately assess quality of life in people using a pump to manage their diabetes. Mixed results for the impact of pump therapy on quality of life seem to be due to poorly chosen or inappropriate measures.

To answer this question, we need to know what issues are relevant and important to pump users. There are currently no qualitative studies into the quality of life issues associated with insulin pump therapy in type 1 diabetes. This study aims to plug this gap, thereby aiding the design and selection of appropriate measures for future studies on pump use.

2. METHOD

Following receipt of ethics committee approval, we conducted an exploratory qualitative study to explore patient experiences of life on a pump. Brief telephone interviews were conducted with current pump users, based on the following key questions. What are the benefits you have experienced from using the insulin pump? Specifically, how do you think it has affected your quality of life? Are there any downsides that you have experienced from using the pump? Are there any other issues these questions have raised for you?

2.1 Participants

Eighty participants were recruited to take part in brief interviews regarding their experience of living with an insulin pump. All participants were current insulin pump users. Roche Diagnostics asked its customers if they would be willing participate in the study. In accordance with ethics approval, only those who gave written consent were interviewed. When a customer phoned Roche Diagnostics' customer services helpline for pump supplies, the interview took place after completing the main purpose of the call.

2.2 Procedure

All eligible participants on the insulin pump users' database (n = 950) were sent a letter outlining the study and asking potential participants for written consent to be approached. Of these, 255 returned signed consent forms. Subsequently, people contacting the customer services helpline, between 12 September 2005 and 12 December 2005, who had returned consent forms, were asked to participate.

To ensure consistency, the authors trained the interviewers. This training included which questions to ask, how to ask them, how to address any responses and, where appropriate, to explore answers. Additionally, the authors provided the interviewers with a written guide

about how to conduct the interviews. If participants gave closed answers to questions, such as a simple 'yes' or 'no', interviewers were encouraged to prompt them a little further. Participants received every opportunity to raise issues. Interviewers generated empathy with participants; they avoided guiding responses towards any particular answer.

All individuals who were invited to participate agreed to do so. Interviewers subsequently put questions to them by telephone, digitally recording each call. Transcription and analysis then took place.

2.3 Analysis

The authors repeatedly read the transcripts and listened to the recordings. This ensured familiarity with the data. Then each interview was analysed separately, noting evident themes or concepts. The authors reduced the analysis down to a meaningful number of constructs: once all interviews were analysed, this initial list of themes was examined and grouped where there was obvious similarity. This was an iterative process. The two authors reached consensus on the themes, before allocating each participant's response a theme. To gauge overall satisfaction, themes were separated into positive and negative.

3. RESULTS

Interviews generally took between five and 10 minutes, but occasionally lasted up to 15 minutes. All participants (n = 80) reported experiencing benefits of being on an insulin pump and that the pump had affected their quality of life positively. (In the following quotes from participants the numbers in parenthesis refer to each patient's code number in the study.)

3.1 Key positive themes

Control *vs* controlled (n = 45), flexibility (n = 33), and freedom (n = 28) were the most cited benefits, followed by convenience (n = 7) and independence (n = 5). See Table 1.

3.1.1 Control vs controlled

Regaining control over their diabetes had a major impact for over half of the participants (n = 45). Feeling that they were in control of their diabetes, rather than being controlled by it, was not only perceived to be a quality of life benefit in itself, but also impacted on other issues such as freedom, independence and flexibility. For example, one participant said:

'My blood glucose control has improved no end, ... erm ... I'm just, just completely different person. It's made my life ... I feel freer than I have for years,' (1073).

3.1.2 Freedom

Twenty-eight participants cited increased freedom as a benefit. Freedom represented the removal of ties and limitations, instead offering participants the opportunity for greater choice in living their lives the way they wanted. Participants had often felt regulated by time constraints when using their previous insulin regimens, whereas pump therapy had relaxed these constraints:

'You don't have to be tied down by time; it gives you more freedom in life and better quality and control,' (1039).

Participants (n)	% of total participants	Theme	Quotes from participants
45	56.25	Control vs controlled	'Well I suppose very much improved diabetic control'
			'Better control of blood sugar levels, very few hypos these days'
33	41.25	Flexibility	'I don' t have to stick to so much of a routine you know with eating and insulin, because before it was very regimental'
			'Flexibility really with what I eat and flexibility, erm, in general'
28	35	Freedom	'You don't have to be tied down by time; it gives you more freedom in life'
			'Well basically fits around the lifestyle a lot better; you're able to do more, not so restricted'
7	8.75	Family effects	'It's given her quality of life and also myself as well'
			'There are benefits to the family and friends'
7	8.75	Convenience	'Greater convenience in so far as it's much easier if you're sitting at a restaurant just to press a couple of buttons than taking out a pen'
			'It's a lot more convenient, fits my life a lot better'
5	6.25	Independence	'It's just sort of made me more independent I don't have to rely on my husband to give me injections or anything'

Table 1. Key positive themes

3.1.3 Independence

Experiencing greater independence, not only for oneself but also for other family members, had positively affected the quality of life of five participants directly. A further seven reported positive effects on family members. Having to rely on another person can steal an individual's independence, the effects of which can build cumulatively:

"... so I don't have to rely on my husband to give me injections or anything ... It is just wonderful, it really is," (1015).

One participant commented that pump therapy had improved his wife's quality of life:

'My wife wouldn't go away and leave me to fend for myself due to the fact I used to have hypos at night. It's totally stopped that and now I can control it and am aware when hypos are oncoming. It's given her quality of life and also myself as well,' (1052).

3.1.4 Flexibility

Increased flexibility was the second most frequent response. Again, this shows that participants found the lack of restrictions was important:

'I don't have to stick to so much of a routine you know, with eating and insulin, because before it was very regimental,' (1073).

The data analysis identified a number of key themes. Participants often mentioned the themes together. Thus, pump therapy improved quality of life through a number of inter-related benefits in combination.

3.1.5 Benefits

Specifically, in response to a question about the benefits experienced whilst on an insulin pump, individual participants' responses were varied with a number of participants reporting very high satisfaction with their insulin regimen, for example, quoting one participant:

'It's the most wonderful thing that has ever happened to me,' (1015).

A second participant said:

'Unspeakable really, marvellous' (1020), with other participants' quotes including: 'It's given me my life back really,' (1024); 'It's completely revolutionised my life,' (1029); 'It has changed my life completely,' (1036); 'More freedom mainly, better control, more confidence,' (1032); and 'It's given me freedom,' (1089).

3.1.6 Reduction in hypoglycaemia episodes/severity

A number of participants highlighted a reduction in episodes or severity of hypoglycaemia as a benefit to insulin pump therapy. One participant reported:

'Very few hypos these days: I used to have them quite frequently, especially during the night.' Another said: 'I still get hypos, but they are less severe' (1041).

Associated with this was a reported reduction in day-to-day blood glucose fluctuations by five participants. It can be very difficult to maintain good blood glucose control, particularly when levels are fluctuating wildly throughout the day. The removal of such erratic fluctuations was cited as providing a quality of life benefit, e.g.

'I'm better because I was having really bad hypos and my blood sugar was flying up, it was really, really erratic and all that's gone,' (1045).

Another participant said:

'I used to yo-yo from very high to very low, which definitely had an effect on how I felt; in that way now it's much more controlled...' (1013).

3.1.7 Comparison with previous insulin regimen

A number of participants compared using the pump to their previous insulin therapy in an effort to highlight the improvements their new regimen offered; for example, one such comparison related to insulin pump therapy having removed the necessity to carry insulin and needles around with them.

'I can go out and only carry my testing kit, without all the other paraphernalia,' (1043).

3.1.8 Effects on quality of life

When asked about how being on a pump had specifically affected their quality of life, there was also variation in responses. Whilst all participants reported improvements in their quality of life, some were more enthusiastic than others. Responses ranged from

"...erm, improved it" (1007) to 'If somebody tried to take it off me I'd fight them and I would go back to paying for it," (1028).

Some of the in-between responses included:

'... you are very free to live. You don't have certain times to eat, wake up and things like that,' (1031); 'It's changed my life really, it's totally back to ... normal,' (1032); and 'I didn't have a life before. Now I can work. I can have a social life...' (1029).

3.2 Key negative themes

In all, 58.75% of participants (n = 47) reported having experienced downsides to using the insulin pump. Topping the negative themes was visibility— device (n = 25), followed by breakdown (n = 17), visibility— skin (n = 5), and cost (n = 3). See Table 2.

Table 2. Key negative themes				
Participants (n)	% of total participants	Theme	Quotes from participants	
25	31.25	Visibility— device	'It's not very easy to wear it's quite heavy and quite bulky'	
			'You have to find somewhere to hide it'	
17	21.25	Breakdown	'Times when I've had some technical problems with the pump went into DKA'	
			'When it goes wrong it goes disastrously wrong'	
5	6.25	Visibility— skin	'I get bruising and bleeding and build up of fatty tissue'	
			'It's the marks on your stomach where you put your insulin'	
3	3.75	Cost	'Well obviously the downside is still paying for things'	
			'Apart from the costing, I don't get funding whatsoever'	

Table 2. Key negative themes

Interestingly, when asked whether they had experienced any downsides to insulin pump therapy, less than half (i.e. 40%) of participants reported having experienced no downsides at all.

3.2.1 Visibility— device

Of the near 60% of participants who had experienced downsides, the majority reported difficulties with the visibility of the pump and its concealment. Within this key theme, responses varied greatly and were particularly individual to participants. Such responses included:

'The size of the pump, the weight of it,' (1004); 'You can't really hide it in a bikini and you've got to make sure you've got the right underwear on when you're wearing a dress,' (1028); 'I think it's very uncomfortable and very intrusive,' (1072).

Pump sizes vary. More modern models are smaller. So issues regarding size and concealment cannot be generalised across participants, not least because participants' particular models of

pump were not known. Also, what may seem trivial to one person may have very serious implications for another. Thus it is impossible to make judgements on the severity of issues without further exploration into their deeper meaning with participants.

3.2.2 Health care professional advice and breakdown

Other downsides included the perceived lack of appropriate health care advice or availability of sufficient trained professionals, as well as what happens if the pump breaks down. This reflected a certain level of frustration by participants that they knew more about the technology and therapy than their first point of contact when they needed assistance. For example, participants' comments included:

'I think when you need some specialist advice,' (1016). Another said: 'There aren't enough health care professionals that know about it or how to deal with people on pumps,' (1044).

'When things go wrong' was an issue raised by 17 participants, reflecting the rapid nature of problems arising when the insulin pump breaks down. Short-acting insulin is used in insulin pumps, necessitating the availability of back-up insulin in case of emergency. It can be an extremely difficult experience, as these comments show:

'When it goes wrong, it goes disastrously wrong,' (1034); ' The times when I've had some technical problems with the pump, erm, there was one time I got, I think it was my cannula was badly sited and I went into DKA,' (1007); ' Yes, I have bubbles in the pump and then that caused ulcers...' (1031).

3.2.3 Cost

Cost was still perceived as a downside by three participants. Even though insulin pump therapy is becoming increasingly available on the NHS, many people are still bearing the costs of their treatment. Comments included:

'Well obviously the downside is still paying for things,' (1006); and '... I don't get funding whatsoever,' (1052).

4. **DISCUSSION**

Insulin pump therapy was not regarded as a miracle cure by participants; indeed, over half of participants reported downsides to pump therapy. As shown in a recent systematic literature review,13 previous research into this area has concentrated on the positives of insulin pump therapy and lack of evidence to support any benefits, specifically when compared with multiple daily injections. It is believed that the reported downsides of the therapy represent a novel and important finding that requires further research. However, participants reported that the therapy offered a chance to live as normal a life as possible. It is the subjective content of the results of this study that provide greatest usefulness in terms of future research. Now measures can be selected based on what insulin pump users report to be important for them rather than researchers imposing their own external judgements on perceived importance. For example, it would be difficult to convey the sentiments of the following statements from an external perspective. One example is:

'It's changed my life really. It's totally back to, I don't know, totally back to normal,' (1032).

Improvements in quality of life meant different things to different people. For some, it involved the freedom to undertake new activities previously restricted under their old insulin regimen. For others, it represented the removal of something unpleasant, such as fear. The comments of one participant highlight this, when asked how pump therapy had affected his or her quality of life:

'Oh it's far better. It's far better because I've got rid of those ups and downs all the time. It was really making me feel ill before. To be honest, erm, I was on my own and I was frightened because I wasn't waking up in the mornings. You know, because I' d gone so bad into a hypo first thing in a morning that I just wasn't waking up. It's made a big difference to me,' (1045).

Not only had insulin pump therapy helped with the blood glucose level fluctuations, it also helped to reduce the fear this participant was experiencing living alone with hypoglycaemia. It would be difficult to capture the essence of this statement in a quantitative measure.

How living with diabetes affects the wider family can sometimes be overlooked. Yet it is tied in with the greater independence that participants reported. A number of participants highlighted the benefits of insulin pump use in the wider context of how their diabetes affected the whole family and how their reduced reliance had knock-on quality of life benefits for other family members. One lady explained:

'I was completely reliant on my family; now I'm living with my partner, I've a job, I have a life,' (1029).

Several participants emphasised the positive effects of insulin pump therapy on family members (n = 7). One participant reported:

'I think people just don't worry about you quite as much as well. I mean my great story is that my mum doesn't go into meltdown when we go to a family wedding any more...' (1028).

Other participants reported that other family members believed insulin pump therapy had had a positive effect. For example:

'Family think it's improved my life,' (1024); 'For the family it's so much easier,' (1026); and 'There are benefits to the family and friends as well; it does touch every aspect really in a positive way,' (1056).

The main purpose of this study was to gain a meaningful insight into how insulin pump therapy affected the lives of people with type 1 diabetes, both positively and negatively. Until now, it has been very difficult to determine what insulin pump therapy really means to people (in terms of qualitative expression). Previous quality of life assessment has concentrated on quantitative methods, which have been unable to capture the essence of subjective experience. Perhaps one of the key strengths of this study is that it highlights the tremendous value a qualitative study can provide. It draws out people's real life experiences and raises new issues such as quality of life benefits of family members. A traditional randomised controlled trial simply could not convey the richness of such data or identify such issues.

A second new and unexpected finding was the positive effect that pump therapy appears to have had on other family members, with participants reporting improvements in their partners' quality of life. This is an issue that requires further research. It is rarely addressed in the literature, because family and partner studies tend to focus on how the partner or wider family influences the quality of life of those with diabetes. Clearly, this is an area that needs more attention.

This study is not without its limitations. However, the authors believe the richness of data strongly outweighs them. It is recognised that this is a specific target group that was accessed through a Roche Diagnostics' customer services helpline. People using insulin pump therapy represent a very small population throughout the UK and Roche Diagnostics currently provide approximately 50% of those insulin pumps. As such, it is believed that a representative sample of pump users participated in this study. As Roche Diagnostics supply the insulin pumps to participants, it must be acknowledged that participants may have felt some obligation to answer questions more favourably than if they had been asked by an independent third party. In answer to this, the authors contend it is unlikely that participants had any reason to be influenced by a relatively unchallenging team member within the structure of such a large organisation. Furthermore, regular contact had established a rapport between customer services staff and participants before the start of this study.

The current study reflects the enthusiasm of participants for pump therapy. Of course, all participants were current insulin pump users. It could be argued that the fact that they choose to remain on a pump reflects their satisfaction with the treatment. Over half of participants reported a wide range of downsides, which may go some way to explaining why a small percentage of pump users return to their previous insulin regimen. One must be cautious when making such an inference, because other issues not identified in this study may influence a person's decision to cease pump therapy. Little is known about this population. Therefore further research into this area would be useful.

In conclusion, for this highly motivated and enthusiastic population, insulin pump therapy has provided important improvements in their quality of life. Insulin pump therapy is sometimes perceived as a demanding therapy and the range of downsides reported by participants may reflect this. Further research is required to establish the long-term benefits and the effects on family members' quality of life. Key issues that researchers should investigate include any long-term benefits associated with insulin pump therapy, specifically what it is about insulin pump therapy that could provide quality of life improvements or whether it is a combination of a cumulative benefit across a range of issues associated with quality of life; furthermore, how to reduce the impact of reported downsides to reduce the demands of the therapy. Now that more is known about people's subjective experience of pump therapy, further research measures might include the IDSRQ (insulin delivery system rating questionnaire) and a generic quality of life measure to determine general vs insulin delivery system specific issues.

Conflict of interest statement

Roche Diagnostics provided an educational grant to carry out the study.

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