

# From 'pleasure to chemistry': the experience of carbohydrate counting with and without carbohydrate restriction for people with Type 1 diabetes

Pip Cresswell RN, MN;<sup>1</sup> Jeremy Krebs MBChB, MD, FRACP;<sup>2</sup> Jean Gilmour RN, PhD;<sup>3</sup> Aoife Hanna BSc;<sup>1</sup> Amber Parry-Strong PhD<sup>1</sup>

## ABSTRACT

**INTRODUCTION:** Matching carbohydrate intake with insulin dosage is recommended management for people with Type 1 diabetes. However, international interest in restricted carbohydrate diets is growing. General practitioners and practice nurses need to know how to advise people with Type 1 diabetes regarding low-carbohydrate diets. This study aimed to explore the carbohydrate counting experiences of people with Type 1 diabetes in a trial with and without a diet restricted to 75 g of carbohydrate per day.

**METHODS:** Eight participants were interviewed by focus group or interview 12 weeks after a carbohydrate counting course with individual dietary choice or the same course with information on restricted carbohydrate eating and a daily maximum intake of 75 g of carbohydrate. Data were analysed using a qualitative thematic analysis approach.

**FINDINGS:** Themes included the need for insulin management skills, impact of the dietary experience, and need for dietary knowledge. The restricted-carbohydrate group encountered mealtime insulin resistance and difficulty managing insulin dosages when transitioning on and off the low-carbohydrate diet. The diet impacted on mood, feelings of satiety and it was reported that food changed from being 'a pleasure to chemistry'. Both groups described feeling empowered to manage their diabetes as a result of the carbohydrate counting course.

**CONCLUSION:** Participants reported increased knowledge and challenging insulin management. The restricted-carbohydrate group reported mealtime insulin resistance and a strong dietary impact. Extra health professional support may be required, especially at dietary transition periods. More research is warranted into the reported mealtime insulin resistance.

**KEYWORDS:** Carbohydrates; diabetes mellitus, Type 1; diabetic diet; qualitative research; self care

<sup>1</sup>Endocrine Diabetes and Research Centre, Capital and Coast District Health Board, Wellington, New Zealand

<sup>2</sup>Department of Medicine, University of Otago, Wellington, New Zealand

<sup>3</sup>School of Nursing, Massey University, Wellington

## Introduction

Carbohydrate counting or flexible intensive insulin therapy (FIIT) is advocated as best practice self-management for people with Type 1 diabetes to achieve good glycaemic management<sup>1-3</sup> and reduce episodes of hypoglycaemia.<sup>4</sup> This approach uses variable mealtime rapid-acting insulin dosages, dependent on carbohydrate intake, combined with long-acting daily background insulin. People with Type 1 diabetes make up between 5% and 10% of the diabetes population.<sup>5</sup> Intensive glycaemic control is necessary to delay microvascular changes.<sup>6</sup>

In the past, people with Type 1 diabetes were encouraged to eat a set amount of carbohydrate at each meal to match with a set dose of insulin. Carbohydrate counting creates the possibility of following more normal eating patterns, with a variable carbohydrate intake. Carbohydrate counting requires skill in assessing the carbohydrate content of food and in calculating the appropriate mealtime rapid-acting insulin dose, using a personalised insulin:carbohydrate ratio.<sup>7,8</sup> The insulin:carbohydrate ratio represents how many grams of carbohydrate one unit of insulin can provide coverage for. Dose Adjustment for

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## CORRESPONDENCE TO:

**Pip Cresswell**  
Endocrine Diabetes and Research Centre,  
Capital and Coast District Health Board,  
PB 7902, Wellington South, New Zealand  
Pip.Cresswell@ccdhb.org.nz

Normal Eating (DAFNE) is an example of a structured education programme that teaches the principles of carbohydrate counting and insulin dose adjustment.<sup>2,3,7</sup> People with diabetes are taught about carbohydrate counting and adjusting their insulin dosage to match carbohydrate intake.<sup>9</sup> Research on the impact of the programme has found improved glycaemic control and reduced episodes of hypoglycaemia, along with weight reduction over one year, in an audit of 145 Australian<sup>10</sup> and 639 UK participants.<sup>11</sup> A longer-term study of 111 UK patients seven years after the programme found a sustained reduction in HbA1c from baseline, along with a small weight gain.<sup>3</sup> The psychological impact of the programme is reported to include reduced diabetes-related distress<sup>11,12</sup> and an increased perception of wellbeing.<sup>10</sup>

Participants have reported making limited dietary changes after the education programme because of factors such as the need for routine, the increased intellectual burden, and the disruption of continually calculating ratios, along with more numerous insulin injections.<sup>7</sup> Some participants reduced their carbohydrate intake partly to avoid injections and partly because they felt anxious about the possibility of insulin miscalculations.<sup>7</sup> Concern was expressed by some participants about unpredictable blood glucose results resulting from eating unfamiliar food, in terms of the carbohydrate content, coupled with large insulin doses. The ability to limit carbohydrates, rather than having to eat fixed amounts linked to fixed insulin dosages, had beneficial aspects for some in terms of weight loss, increased mealtime flexibility, and feelings of more predictability and control over blood glucose readings.<sup>7</sup>

Low-carbohydrate diets for people with Type 2 diabetes have been the subject of research interest,<sup>13–15</sup> with findings of improvements in glycaemic control and weight loss. There are fewer studies of this dietary choice in people with Type 1 diabetes.<sup>16–18</sup> One study with 48 participants found the average HbA1c was reduced three months after education, and that half the participants maintained a clinically significant drop over four years.<sup>16</sup> With rising international interest in low-carbohydrate diets, people with Type 1 diabetes are increasingly asking clinicians whether a low-carbohydrate diet would be beneficial.

The aim of this research was to explore the experiences of people with Type 1 diabetes who took part in an existing clinical trial comparing a standard carbohydrate counting course with individual dietary choice for the following 12 weeks (SCC), or the same course with additional information on low-carbohydrate eating and a maximum daily intake of 75 g of carbohydrate (LCC).

## Methods

This sub-study used a qualitative, descriptive approach<sup>19</sup> and focused on an in-depth exploration of the experiences of participants with Type 1 diabetes undertaking major dietary changes in conjunction with an education course.

Eight participants were recruited into this sub-study from a pilot randomised controlled clinical trial with 10 participants carried out between March and May 2013 after ethics approval (Ref. 13/CEN/16 New Zealand Health and Disability Ethics Committee: Central Application). The trial compared the effects of standard carbohydrate counting and individual choice of carbohydrate intake with carbohydrate counting and a restricted-carbohydrate diet of 75 g of carbohydrate per day in terms of glycaemic control, quality of life and renal function. Participants attended eight hours of group carbohydrate counting sessions over four weeks, with two one-on-one follow-up sessions delivered by a diabetes nurse and a dietitian. Course content included explanations of what carbohydrate is, calculating and changing insulin dose, carbohydrate ratios, correction doses, and managing illness and exercise. Extra content on low carbohydrate eating was provided to the group following the 75 g of carbohydrate per day restriction. The participants could choose how they ate apart from maintaining this restriction. Both courses were run concurrently.

After completing the trial, eight of the 10 participants consented to be part of this qualitative sub-study. Focus groups (interactive group interviews on a defined topic<sup>20</sup>) were organised and two participants attended the SCC group, and four the LCC focus group. Two people from the SCC group who could not attend the focus group were interviewed individually. The two-hour focus

groups were run by two researchers, one acting as moderator and the other researcher intervening for clarity as needed. The interviews followed a question guide informed by DAFNE publications.<sup>7,9</sup> Topics included experiences of dietary changes, impact on lifestyle, and satisfaction (see Table 1). The interviews were transcribed and pseudonyms were used from the outset to ensure confidentiality and privacy.

An inductive analysis was used to review the study data,<sup>21</sup> along with thematic analysis as described by Braun and Clarke.<sup>22</sup> The process involved coding, and the within-group data were compared and contrasted with the other group data. All the categories were data driven. The categories were then ordered into overarching themes with subthemes. The first author performed an initial analysis and then the third author reviewed both the transcripts and analysis to confirm that the analysis linked to the original data.

To ensure validity in qualitative research, triangulation of data was used,<sup>21</sup> by checking collected data as much as possible with other sources. Data provided by one participant were almost always verified by at least one other interviewee.

## Findings

The themes identified covered three areas: insulin management skills, dietary experience, and dietary knowledge. There were differences and similarities in the experiences reported by the LCC and SCC groups.

### Insulin management skills

The participants started with varied diabetes management skills, attitudes and experience. Mealtime insulin dose adjustment is a complex process that participants encounter several times a day, even when not carbohydrate counting. Participants used their experience to help determine an appropriate dose, taking into account other factors that affect their blood glucose levels, and the blood glucose results achieved are not always as expected.

I'm supposed to go dancing tonight so I might tailor it a wee bit... I'll see how I go and I'll adjust... so if

## WHAT GAP THIS FILLS

**What we already know:** Flexible intensive insulin therapy is recommended as best practice self-management for people with Type 1 diabetes. Some people with Type 1 diabetes choose a restricted low-carbohydrate diet to achieve more predictable blood glucose levels.

**What this study adds:** More diabetes management now occurs in primary care with specialist support, so general practitioners and practice nurses need to know how to advise people with Type 1 diabetes on restricted-carbohydrate diets. Restricted-carbohydrate dietary changes had marked effects on the people with Type 1 diabetes in the study and may require extra health professional and educational support, especially during dietary transition periods.

Table 1. Focus group questions

<b>Experience</b>	How did you find the carbohydrate counting? How did you find the low-carbohydrate diet (if appropriate)?  Why did you want to do the course? Was that achieved? Why/why not?
<b>Impact on lifestyle</b>	Was there any effect on your lifestyle? Describe these effects. Are they important? A problem? Sustainable?  Has there been any effect on your diabetes management? If yes, please describe.  The idea of carbohydrate counting is to free up your eating. How has that worked/not worked?  What are your thoughts about keeping on with carbohydrate counting? With the low-carbohydrate diet (if appropriate)?
<b>Satisfaction</b>	What were the negative points?  Were there good points?  Any difference between your expectations and your experience? Please explain.

it's below 9... then I'll eat something before I start.  
(#1; LCC Group)

Learning to titrate insulin dosage to match carbohydrate intake was challenging for participants in both research groups, and two subthemes emerged: mealtime insulin resistance and dietary transition difficulties.

### Mealtime insulin resistance

The most striking difference between the two dietary groups was the unexpected mealtime insulin resistance reported by three of the four LCC participants.

[I don't know] ...whether your body just craves more insulin or you become more resistant to insulin...  
(#2; LCC group)

Although participants in the LCC group decreased their overall insulin dose as expected, the amount of mealtime insulin increased relative to the amount of carbohydrate consumed. Initially, there were reductions in insulin doses with one person reducing insulin dose to almost a third of his previous total daily dose of insulin of 104 units. Once established onto the low-carbohydrate diet, two participants reported doubling mealtime insulin from ratios of one unit of insulin to 4.5 g of carbohydrate (1:4.5) up to a ratio of 1:2.

I went from being 1:4.5 to 1:2 [insulin:carbohydrate ratio]... I realized I wasn't taking enough insulin... I was taking too much overnight and not enough during the day... My ratios had to change quite quickly and then going back to the normal diet, it's been the same again. (#3; LCC group)

In contrast, there was a more straightforward relationship between diet and insulin management reported by those in the SCC group, with one person commenting:

...My insulin intake has gone down by targeting my insulin to what I'm actually eating. (#4; SCC group)

#### *Dietary transition difficulties*

Both groups experienced difficulty with dietary transitions. One difficulty experienced by the LCC group was the 'steep learning curve' of having to apply new skills of carbohydrate counting and carbohydrate restriction simultaneously. The most challenging aspect reported by this group was transitioning on and off the low carbohydrate diet to an unrestricted carbohydrate diet.

The change in diet went suddenly from one day full on to the next day to the reduction which I think was a mistake... It should have gradually just tailed off... and I had problems because I do a lot of physical work so there were occasions where I just had to basically binge. (#5, LCC group)

Returning to an unrestricted-carbohydrate diet with the very high ratios they had become accustomed to was unlikely to be safe. For example, one participant's previous breakfast of muesli, milk and fruit contained 90 g of carbohydrate for

which he took 20 units of rapid-acting insulin, a ratio of 1:4.5. On the low-carbohydrate diet, he required a 1:2 ratio and if he continued with this ratio he would have taken a 45 unit rapid-acting insulin dose for a 90 g carbohydrate breakfast. We recommended that during transition back to a normal diet, participants start with the initial ratio determined for them at the beginning of the course based on their carbohydrate intake at the time and then adjust their ratios based on their blood glucose results.

The SCC group struggled with dietary transitions in terms of translating theory into practice. Two SCC participants did not learn all the skills required to use and change insulin:carbohydrate ratios and instead became product label readers. They started identifying high carbohydrate products and avoiding those food types:

I probably did it [carbohydrate counting] intermittently for the duration of the course but beyond that it just got away quite quickly for me ...so I've just been doing what I normally do. (#6; SCC group)

Applying theory to practice is recognised as difficult<sup>23</sup> and these participants reported not using ratios due to family responsibilities and work demands intruding on the time required to learn new skills.

#### **Dietary experience**

The marked change in diet for the LCC group led to strong reactions. Within this theme there are two subthemes: confronting diabetes and the impact of dietary changes.

##### *Confronting diabetes*

The combination of learning to carbohydrate count and restricting carbohydrate intake led to people in the LCC group feeling quite 'confronted' by their diabetes. Most of them normally managed their diabetes 'quietly' and privately, but the course and the dietary alteration required constant work and put their diabetes 'front and centre' in their lives.

I guess I'd sort of coped as if I didn't have diabetes to now I actually have diabetes and I've got to do

all this stuff... It does change the whole concept of having diabetes and I found that very depressing because up till then I felt like I was normal. (#2; LCC group)

Diabetes for me was like another child... It was just something I looked after and I didn't put it in everybody's faces... I didn't even inject and test in front of people. I just got on with it... but everybody started seeing me reading labels profusely and measuring things. (#7; LCC group)

Participants in the SCC group reported a more relaxed experience, incorporating carbohydrate counting into everyday routines.

#### *Impact of dietary changes*

Members of the LCC group felt that overall it was worth the effort to improve their diabetes management, but reported a significant impact on mood and feelings of satiety. The dietary experience was reported as all-consuming and participants' reports ranged from finding it 'fantastic' to 'hating it'.

I found [it] fantastic but... quite full on. (#7; LCC group)

The course changed food from a pleasure to chemistry basically. Suddenly my enjoyment of meals went down considerably. (#2; LCC group)

Initially, the participants in the LCC group reduced carbohydrate intake without replacing it with sufficient other food, and several reported feeling intense hunger. Three of the LCC group reported struggling to include fruit in their diet due to its high carbohydrate content, although most participants had compensated for this by increasing their vegetable intake.

Weight loss was a potential effect of being in the restricted carbohydrate arm of the trial.

Losing the weight has been an unexpected benefit and I think that probably means I will try and keep certain aspects of the low-carb diet, like the breakfast and the low-carb bread. (#3; LCC group)

Others in the LCC group did not lose weight, attributing that to already being on a relatively

low-carbohydrate diet before participating in the trial and having a less dramatic change in diet. Those who lost weight considered the low carbohydrate diet a tool they could use again to lose weight, if required. Weight management was of great interest to the participants in the SCC group also and participants were pleased that their weight was stable over the trial period.

#### *Dietary knowledge*

Participants in both groups identified carbohydrates as a concern because they raise blood glucose levels and raise them unpredictably. LCC group participants reported difficulty in understanding why mealtime insulin dosages increased and the SCC group expressed the view that carbohydrates caused unpredictability. However, both groups indicated they felt empowered through the knowledge they had gained.

#### *Carbohydrates are negative*

Both groups viewed carbohydrates negatively once they associated blood glucose levels and carbohydrates specifically. They related carbohydrates to unpredictable blood glucose levels and long-term complications of Type 1 diabetes. Rather than feeling a sense of greater freedom with their eating choices as a result of their carbohydrate-counting skills, members of the SCC group elected to eat less carbohydrate. They said they chose to do this as reducing blood glucose level fluctuations and maintaining a consistent weight was of far greater importance to them than being able to eat more freely.

I'm finding I'm not eating as much carbohydrate as I... you become more aware of what food has in it and how much carb [carbohydrate] it has in it... It's quite horrific really. (#2; LCC group)

This reduction in carbohydrates occurred despite the aim of carbohydrate counting being to enable people with Type 1 diabetes to have more choice about what they eat, in a similar way to people without diabetes.<sup>7</sup> Past experience had made participants wary of unpredictability and fluctuations in blood glucose levels.



Both groups noted that carbohydrate counting was not the entire answer for managing their diabetes.

Carbohydrate counting makes a good starting point because sometimes those factors work and sometimes they don't. I still fluctuate [have varying blood glucose levels] a fair bit. (#1; SCC group)

I've got a lot of questions about carbohydrate counting and how it works because there's quite a few anomalies as I see it. (#3; LCC group)

While participants reported seeing value in carbohydrate counting, both groups considered it a tool with limitations.

#### *The need for guidance*

The information sheet for the trial explained that the effect of a low carbohydrate diet on people with Type 1 diabetes was unknown. However, both participants and health professionals involved were surprised at the apparent mealtime insulin resistance experienced by the LCC group:

And no-one could explain that [the higher insulin:carbohydrate ratio required on the low carbohydrate diet]. (#2; LCC group)

Participants were disappointed that explanations were not immediately apparent for this experience. They indicated that they would have preferred to have more guidance about healthy low-carbohydrate eating, specifically, that more recipe and substitution suggestions and low-carbohydrate menus to follow would have been useful.

#### *Empowerment*

Both groups reported being on the course with other people with Type 1 diabetes was a positive experience.

[It makes you] feel a bit normal. (#7; LCC group)

[You realise] you're also not alone... You see how 'across the board' it is [how others with Type 1 diabetes experience similar issues] (#1; SCC group).

Participants in both groups also felt empowered by the knowledge gained through the classes.

It's also a great sense of awareness and I think once you work through that and do it a few times it's quite empowering actually. (#5; LCC group)

You target the insulin to the food... whereas before you targeted it to the quantity of the food which caused me problems. (#4; SCC group)

Prior to taking part in the trial, members of both groups ate to match a fixed mealtime insulin dose previously suggested by a health professional.

## **Discussion**

The focus group discussion highlighted the unexpected finding that mealtime insulin doses were significantly increased in the LCC group while, as expected, their background insulin doses reduced. Explaining this is difficult. Increased ketogenesis, and therefore insulin resistance, may be expected to increase during carbohydrate-restricted diets.<sup>24</sup> However, ketogenesis was not evident in the pilot trial. Participants were asked to test for blood ketones at least weekly and if their blood glucose levels were higher than 15 mmol/L. Only one episode of elevated blood ketones was reported, which was attributed to intensive exercise despite having an elevated starting blood glucose level.

The reported mealtime insulin resistance could have been caused by a negative effect on insulin sensitivity due to an increase in saturated fat<sup>24</sup> in the LCC group's diet, but the main study showed there was no increase. Insulin dose requirements may have been partially affected by inaccurate carbohydrate counting, as has been reported elsewhere;<sup>25</sup> another possibility is that in people with a limited carbohydrate intake, gluconeogenesis becomes such an important source of glucose that it becomes necessary to also calculate the protein content of a meal and use an insulin:carbohydrate and protein ratio.<sup>26</sup> Mealtime insulin resistance in people with Type 1 diabetes on low carbohydrate diets has not been reported elsewhere, and this finding requires further exploration to see whether it has relevance for other people with Type 1 diabetes who may wish to try low-carbohydrate eating.

The limited literature on low-carbohydrate eating in people with Type 1 diabetes suggests that a 70–90 g carbohydrate limit per day is safe and tolerable.<sup>17</sup> While most of the LCC group reported feeling ‘starving’ at the beginning of the trial, this was largely because they had difficulty with substituting high-carbohydrate foods and simply reduced their overall intake. Over the course of the trial, participants tended to replace carbohydrate with more protein and to tolerate the 75 g of carbohydrate limitation well. Some participants expressed delight with the resulting weight loss.

Difficulties with dietary transition have not been reported in previous research which was quantitative.<sup>17</sup> These difficulties may have been compounded by the rapid transition to low-carbohydrate eating. Our Centre’s usual carbohydrate counting programme is taught over eight hours, with two half-hour follow-up sessions over two months; this approach was used in the trial. In other research trialling low-carbohydrate eating with people with Type 1 diabetes, participants received 16 hours’ education over two months.<sup>17</sup> This increased input could have prepared participants better for their experience and improved the dietary transition experiences compared to our participants who requested more dietary guidance.

The finding that members of the SCC group elected to eat less carbohydrate in order to maintain weight and reduce blood glucose fluctuations is similar to the DAFNE Study findings.<sup>7</sup> Lawton et al.<sup>7</sup> found that rather than providing greater freedom and flexibility, FIIT or carbohydrate counting may encourage more routine.

Despite the LCC group reporting that they got insufficient information about eating well on a carbohydrate restriction and that some SCC participants reported not being able to use insulin:carbohydrate ratios, both groups reported feeling empowered and having more control over their diabetes management. As many people with diabetes have a primary goal of taking control of their disease management,<sup>27</sup> it appears that learning to carbohydrate count and restricting carbohydrate intake are two useful tools to assist self-management.

## Limitations

The overall participant numbers were low for each dietary group and the results cannot be generalised to all people with Type 1 diabetes. Participants were unable to choose which arm of the trial they were in; factors such as choice and interest may have made a significant contribution to the participants’ view of their dietary experience.

## Recommendations

Increasingly diabetes management is occurring in primary care and it is useful for primary health care professionals to be aware of the empowerment people with Type 1 diabetes can feel after education about carbohydrate counting and restricting carbohydrate intake. It is useful to know that, for people with Type 1 diabetes, following a carbohydrate restriction of 75 g per day requires effort and vigilance to manage insulin adjustments and that extra health professional support may be required during transition periods. Further research should be undertaken to explore the reported mealtime insulin resistance experienced by the LCC participants and effective dietary transition practices. Additional education dedicated to low-carbohydrate eating should be developed, incorporating feedback from the LCC participants. This education should include favourite foods substitutes and example eating plans for at least two full weeks.

## Final comments

The experiences of participants in this dietary trial varied widely, but insulin management was challenging for both groups. Members of both groups reported that their increased knowledge was empowering, but also that carbohydrate counting did not always work for them. There were issues for the LCC group, with dietary impact and reported greater resistance to mealtime insulin. Extra health professional support may be required, especially at dietary transition periods. More research is warranted into the mealtime insulin resistance reported by participants in this study.

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## COMPETING INTERESTS

None declared.