

Experiences of the DAFNE structured education programme, and managing type 1 diabetes during Covid-19: A photovoice project

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Executive summary

Why did we carry out this study?

Good self-management is an important part of diabetes care. Structured education programmes, like the Dose Adjustment for Normal Eating (DAFNE) programme, which teach self-management principles, can help support people living with type 1 diabetes. The DAFNE programme has been shown to improve health outcomes, and it is currently being rolled out to more hospitals across Ireland. Only a few studies have explored how people apply learning from the DAFNE programme in everyday life. None to date have explored DAFNE graduates' experiences of managing their illness during the Covid-19 pandemic.

What was the aim of the study?

We wanted to learn about the strengths and weaknesses of the programme, and ways to enhance the programme in Ireland. We had two aims:

1. To explore experiences of the DAFNE programme among people with type 1 diabetes. This includes finding out how people apply their learning from the programme in everyday life.
2. To explore how graduates experienced the Covid-19 pandemic.

What was involved?

Ten people with type 1 diabetes who had completed the DAFNE programme took part in this study. Participants took photographs over a 10-day period to capture their experience of the DAFNE programme and their experience of the Covid-19 pandemic. Participants discussed their photographs and the stories behind them during an online interview with a member of the research team.

What did we find?

Participants had attended a DAFNE programme between 2005 to 2022. Three attended the programme online during Covid-19 while seven attended the standard programme in-person pre-Covid-19 which takes place over 5 consecutive days or six weeks.

Experiences of the DAFNE programme

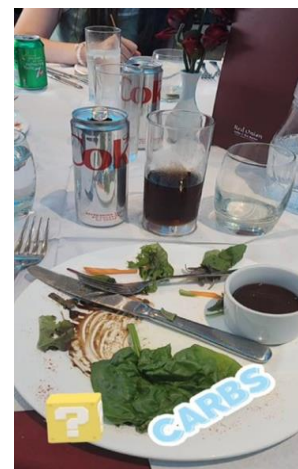
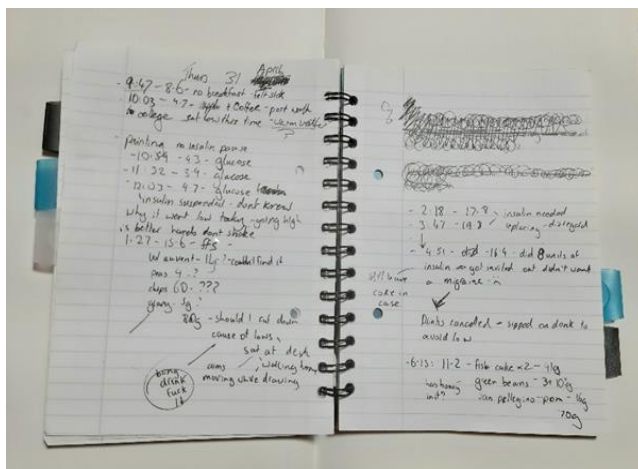
Some participants felt the DAFNE programme gave them more flexibility and freedom in terms of engaging in exercise and making dietary choices. However, people had mixed views on applying the course learning (for example, carbohydrate counting) to everyday life. Some found it easy to apply the skills of carb counting while others felt it was time-consuming, stressful, and difficult. One participant felt the content and format of the DAFNE programme could be more tailored to suit people's needs and different lifestyles. A number of participants expressed frustration after experiencing a long delay waiting to access the DAFNE programme.

Living with type 1 diabetes during the Covid-19 pandemic

Participants felt particularly vulnerable during Covid-19. The pandemic both disrupted some aspects of their diabetes self-management but supported other aspects. For example, during 'lockdown' some people felt they had more control over their diet. There were less opportunities to eat out in restaurants and there was less pressure to socialise. During the pandemic some participants attended medical appointments online. They felt more health services, including DAFNE, should be delivered in this way to shorten wait times and improve access.

Supporting people living with type 1 diabetes

Some participants used their photographs to capture the need for other forms of support when living with Type 1 diabetes. Some highlighted how technology helps them to manage their diabetes, for example, continuous glucose monitoring. Others discussed how important it is to be supported by others in their lives, including friends, family members, and colleagues. Some did not feel supported in their workplace and felt that they needed to hide their diabetes. Participants discussed the mental and physical toll of diabetes, and the risk of burnout as 'you don't get a holiday from it'.



Abstract

Background

Structured education programmes for type 1 diabetes (T1DM), such as the Dose Adjustment for Normal Eating (DAFNE) programme, which teach self-management principles, have been shown to improve clinical outcomes. We explored the experiences of DAFNE among people with T1DM and how learning from the programme is applied in everyday life. Since life events may govern self-management practices, we also explored how graduates experienced the Covid-19 pandemic.

Methods

We used the photovoice method. Participants were asked to take 5-10 photographs over a 10-day period, after which they took part in an online interview to discuss their photographs. Interviews were recorded, transcribed, and summarised on a Rapid Assessment Procedure sheet and photos then linked to the different themes developed from the interview data. Photos and matching quotes were reviewed by participants to ensure selected quotes aligned with the photos.

Results

Ten DAFNE graduates from three major hospital groups took part, returning 60 photos. Participants attended DAFNE between 2005 to 2022, online (n=3) and in-person (n=7). Nine themes were developed related to experiences of the pandemic, DAFNE and diabetes management more generally. While participants highlighted the flexibility and freedom afforded by the programme, there were mixed views on the application of the course principles (for example, carbohydrate counting) to everyday life; some found it easy while others felt it was time-consuming, stressful, and difficult. One participant felt the content and format of the DAFNE programme needs to be better tailored to suit people's needs and different lifestyles. Participants expressed frustration after experiencing a long delay to access the DAFNE programme. Those who attended online medical appointments during Covid-19, felt that more health services, including DAFNE, should embrace this format to shorten wait times and improve access. Lastly, participants highlighted the important role of technology, support (and lack of support) from others in their lives, and diabetes burnout.

Discussion

Our findings highlight the flexibility and freedom the DAFNE programme offers graduates to engage in exercise and make dietary choices. However, the findings also point to how the programme can be enhanced, for example by tailoring the programme content and format, continuing, or starting to offer the programme online to support greater access, and taking steps to embed psychological support and manage burnout.

Background

Type 1 diabetes

Type 1 Diabetes Mellitus (T1DM) is a chronic metabolic disease characterised by hyperglycemia which is caused by defects in insulin secretion resulting from autoimmune destruction of the β -cells of the pancreas (1). Global Diabetes prevalence rates from 2020 are estimated at 9.8% (2). The absence of a National Diabetes Registry in Ireland makes it difficult to determine the prevalence of T1DM, however data modelled from the Scottish Diabetes Registry suggests that approximately 266,664 people are living with diabetes of which 10.8% have T1DM (3). If not correctly managed, diabetes can lead to many serious complications such as damage and failure of various organs particularly the eyes, blood vessels, heart, nerves, and kidneys, making the condition a leading cause of cardiovascular disease, kidney failure, retinopathies, lower limb amputations and premature death (2).

Structured diabetes education

Diabetes management involves trying to achieve optimal glycaemic control by maintaining a low level of HbA1c without frequent hypoglycemia (4). Poor glycaemic control, or higher HbA1c levels, is associated with an increased risk of complications, whereas better control has been shown to increase the frequency of severe hypoglycaemia (5). Self-management of diabetes is therefore a key component of effective care.

Structured education programmes which incorporate experiential learning and skill-based training are increasingly recognised as a method of facilitating self-management (6). The concept of an “Insulin Treatment and Teaching Programme” was first operationalised in Düsseldorf in the late 1970s by German diabetologist, Michael Berger, and his team. This approach was widely adopted across Germany after Berger’s team demonstrated in randomised controlled trials that the approach led to improved glycaemic control in participants (7). This approach was later adapted into the Dose Adjustment for Normal Eating (DAFNE) Programme in the UK in the late 1990’s. Following publication of the results of the DAFNE multi-centre randomised controlled trial in 2002, the DAFNE collaborative was formed with courses now being delivered in 91 sites across the UK and Ireland (8).

DAFNE was introduced to Ireland in 2003 and was recommended for roll-out in the national clinical guidelines for adults with type 1 diabetes published in 2018 (9). The programme is traditionally delivered as a small group-based outpatient programme over 5 consecutive days by a multidisciplinary team (10). The programme promotes dietary flexibility by emphasising regular blood glucose testing, carbohydrate counting and self-titration of corrective insulin doses. Previous studies have highlighted that successful long-term self-management of chronic diseases requires

individuals to be able to integrate these self-management behaviours into daily routines (11, 12). This is the underlying principle of structured education programmes such as DAFNE.

To date, evaluations of DAFNE, both in the UK and Ireland, have focused on effectiveness and psychosocial outcomes (13), showing clear improvements in HbA1c level and quality of life as well as reductions in the frequency of hypoglycaemic incidents among participants of the programme (14, 15, 16). Some qualitative studies have focused on factors influencing participant's self-management after the programme (17) and participant experiences of assimilating the programme principles (13), as well as barriers to accessing the programme (18, 19). However, participant perspectives of how self-management is integrated into daily life remain underexamined (17). The findings from the limited qualitative work (13,17) emphasise the importance of further exploring the part the programme plays in people's daily lives, gaining a greater understanding of their experiences of the programme and seeking new ways to highlight those experiences.

The impact of Covid-19 on self-management of type 1 diabetes

Studies have suggested how the Covid-19 pandemic and resultant lockdown impacts self-management among people with T1DM, leading to a deterioration in glucose control due to factors such as increased stress, restricted outdoor physical activity, potential supply issues and reduced control over daily routines (20, 21, 22, 23, 24, 25, 26). Interestingly, there have also been studies which reported increased glycaemic control in this group during 'lockdown' (27, 28). Qualitative research has indicated this 'lockdown effect' may be due to a slowing of daily routines, increased use of telemedicine and alternative online health services, and greater risk awareness about Covid-19 complications, causing people to stick more rigidly to self-management principles (20, 29). To our knowledge, no studies to date have explored experiences of the pandemic among people with T1DM who have attended structured education like DAFNE.

Aims and objectives

Therefore, in this study, we aimed to gain a further insight into experiences of the DAFNE programme as well as how DAFNE graduates experienced the Covid-19 pandemic. This may highlight areas needing attention as well as strengths, weaknesses, and opportunities for the programme to be enhanced. The way in which people and the environment influence self-management of T1DM may be difficult to elicit through traditional research approaches. Therefore, we used photovoice - a research method whereby participants use photographs to capture meaningful aspects of their lives and explain their significance in a subsequent interview (30).

Methods

Design

Photovoice is a research method whereby participants capture photographs of meaningful aspects of their lives and explain their significance in a subsequent interview (30). It is a unique research method that places participants at the centre of the research process by allowing them to communicate their community's concerns and lived experiences through photographs and accompanying dialogue. Photovoice has been used previously in a range of settings to explore a variety of health and social issues such as the chronic pain experience in older adults (31), the experience of managing diabetes while homeless (32) and the role of technology in physical activity for adolescents with T1DM (33). The method is recognised as a valuable reflection and evaluation tool in health services and social research as it offers the opportunity to highlight an 'insider' perspective of a community. Furthermore, the combination of visual and descriptive output generated in a photovoice project can serve as an engaging educational tool (30).

Photovoice was adopted to explore participants' experiences of self-managing their diabetes after attending a DAFNE programme and living with the condition during the Covid-19 pandemic. There were three stages to the project (**Figure 1**) including an initial online briefing session with participants and follow up interviews to discuss the significance of their photos.

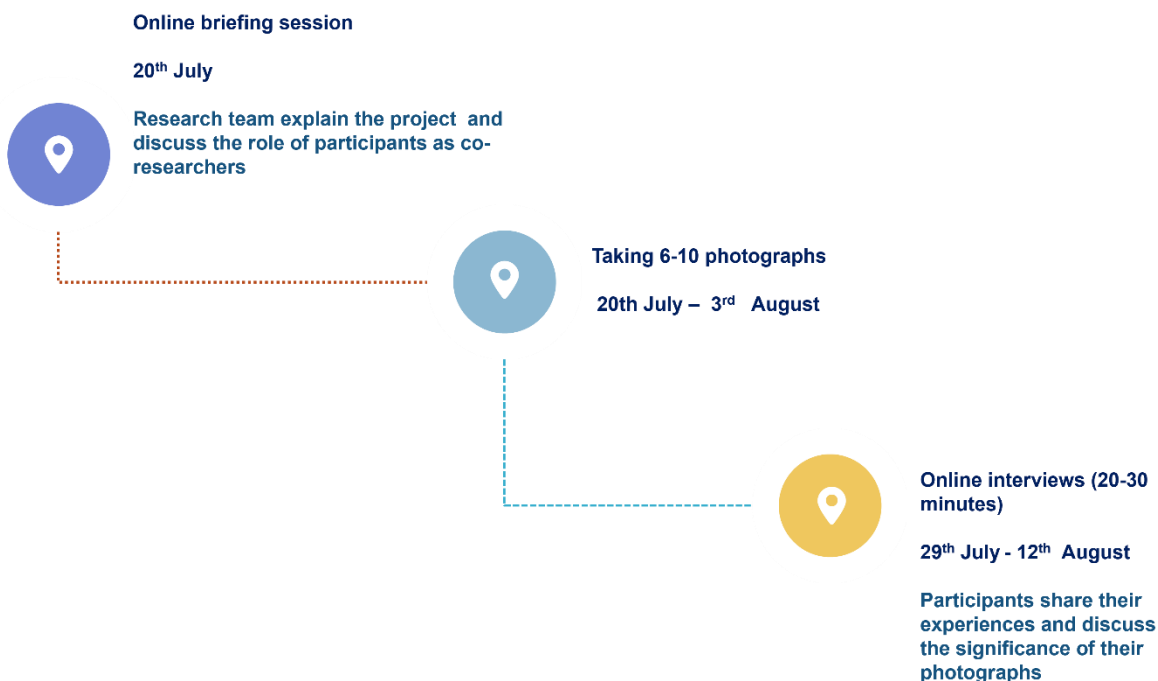


Figure 1: Overview of study data collection

Recruitment

Participants were recruited during a three-week period from 20th June to 4th July 2022. Different recruitment avenues were used to reach DAFNE graduates from different parts of Ireland:

- A patient advocate known to the research team was asked to post information about the study on T1DM support pages on Facebook and Twitter.
- The study was advertised on the Diabetes Ireland website and the charity retweeted about the study.
- The flyer was shared via the research group (Health Implementation Research Hub) on twitter.
- DAFNE educators, from four hospitals, known to the team via the CUSTOMISE project, which is exploring the implementation of the DAFNE programme across Ireland, were asked to email information about the study and the flyer to their graduates.
- Members of the CUSTOMISE PPI panel known to have attended DAFNE were asked to highlight the study within their network.

Potential participants received the information flyer which included details of how to contact researchers by phone or email if interested. Individuals who contacted the researchers were sent a project information sheet and consent form to be signed and returned before participation. Researchers did not have access to individual contact details unless they were contacted by participants.

Data collection

Briefing session

A 1.5-hour group online meeting was held with participants via Microsoft Teams to brief them on the photovoice method and deliver short training on photography. The meeting was facilitated by FR and AK. During this session participants could ask questions and clarify any elements of the study. They also had the opportunity to briefly flag any thoughts on DAFNE and their experiences of COVID-19. Following this session, participants were asked to take 6-10 photographs over a ten-day period (20th July - 3rd August).

Interviews

Brief online interviews (on average, 31 minutes) were conducted via Microsoft Teams to discuss the photographs, giving participants an opportunity to contextualize and explain their images. A semi-structured topic guide informed by guidance from other researchers within the School of Public Health who had used the photovoice method and examples from the literature. FR and AK discussed and revised the guide together and made changes as required.

Like photovoice interviews in other projects, researchers used prompts to explore the significance of the photographs discussed and to elicit how the photos captured participant's experiences and feelings (34). Participants also had an

opportunity to discuss their experiences of attending DAFNE and the Covid-19 pandemic. Interviews were recorded and transcription was generated on Microsoft Teams. The transcript was then edited while listening back to the recording to fix errors. Next, the responses were summarised on a Rapid Assessment Procedure (RAP) sheet which was imported, alongside the photographs, and any accompanying narrative summaries provided by participants, into NVivo version 20 software to manage the analysis. A Rapid Assessment Procedure (RAP) sheet is a tool (structured Word document) used in qualitative research to summarize emerging findings. The intention is to be able to share the findings while the study is ongoing. In the current study, a RAP sheet was used per participant to summarise interview content relating to each photo. Direct quotes from participants were included in these summaries where they particularly illustrated the point being made through the photo (35). Prior to uploading the data to NVivo, a unique ID number was assigned to all transcripts, followed by removal of identifiers including names, occupational details, and organisation names. All data were stored electronically on the password protected UCC OneDrive, including the pseudo-anonymised transcripts, key linking participants to ID numbers, audio and video recordings, consent forms, participant contact details, and briefing session attendance. These were only accessible to members of the research team through an encrypted PC or laptop.

Data analysis

Coding was carried out in three phases following the steps of Braun and Clarke's thematic analysis (36). During phase one each RAP sheet and narrative summary (if provided) was open-coded. Open codes were then organised under the higher-level categories: 'Descriptive information on DAFNE', 'Experiences of DAFNE', 'Experiences of COVID-19' and 'Other forms of support for type 1 diabetes'. The codes generated in phase one were subsequently refined during phase two coding. Lastly in phase 3, codes were organised into themes which were developed under each of the overarching categories. The photos were then linked to the different themes and the matching quotes. These were sent to participants for review to check that the selected quotes aligned with the photos and accurately represented their views.

Ethics

Ethical approval was granted for this study by the UCC Social Research Ethics Committee on 13th June 2022.

Results

Participant characteristics

A total of twelve people gave their consent to participate and attended the initial briefing session. At this point two dropped out and the remaining ten participants returned a total of 60 photos. The number of photos returned per participant ranged between 2 and 10 photos. Three participants provided accompanying written narratives for their photos separate to the interview. All 10 participants took part in interviews which lasted between 19 and 54 minutes

(mean duration of 31 minutes). The final sample of ten participants included eight females and two males attending diabetes services in three different hospital groups (**Table 1**). The year of diabetes diagnosis ranged from 1975 to 2012. Time between diagnosis and attending the course for participants in this study ranged from 2-3 months to 43 years. Participants had attended a DAFNE programme between the years of 2005 to 2022; three attended online due to the Covid-19 pandemic while the remainder attended the standard programme pre-Covid-19 over 5 consecutive days or six weeks.

Themes

The results are presented under broad categories informed by the research questions: 1) Experiences of the Covid-19 pandemic, 2) Experiences of DAFNE and 3) Other forms of support for type 1 diabetes. A total of nine themes were developed across these three categories (**Figure 2**).

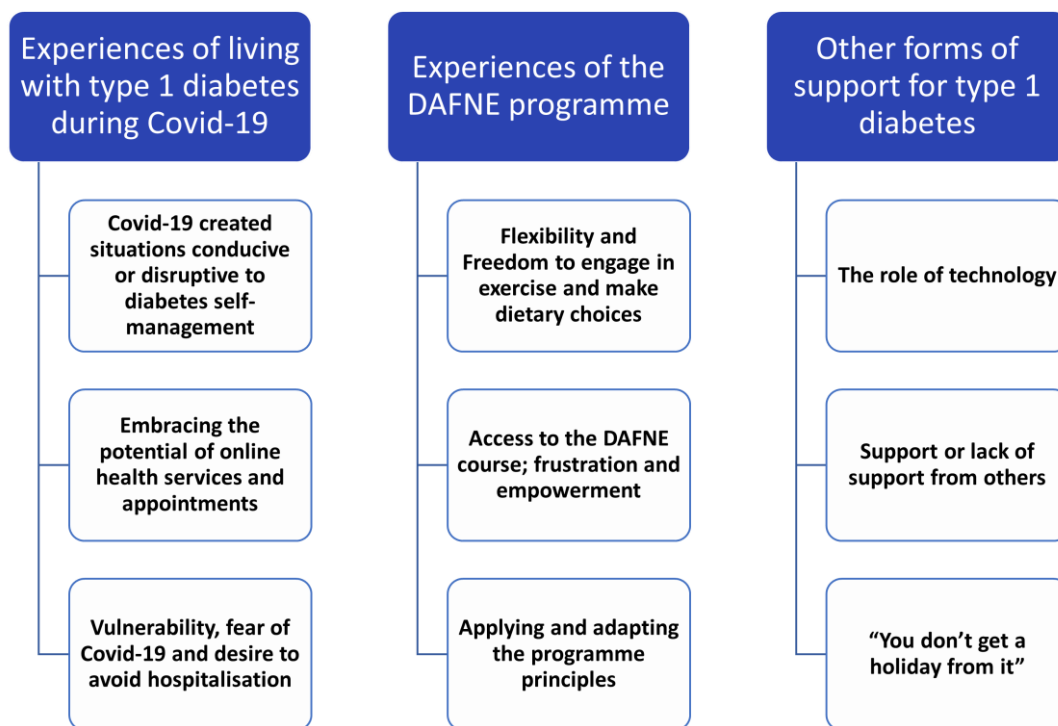


Figure 2: Overview of themes

Experiences of living with type 1 diabetes during Covid-19

Three themes related to experiences of the Covid-19 pandemic: (a) Covid-19 creating situations conducive or disruptive to T1DM self-management, (b) Value of online health services and appointments - needing to embrace this approach more, (c) Vulnerability, fear of Covid-19 and desire to avoid hospitalisation.

Covid-19 created situations conducive or disruptive to diabetes self-management

Participants reflected on the opportunities that the Covid-19 pandemic and resultant 'lockdown' brought about which were conducive to the management of their diabetes. These included the benefits of working and studying from home in terms of the ability to work around their own schedule more, and a reduction in workplace related stress:

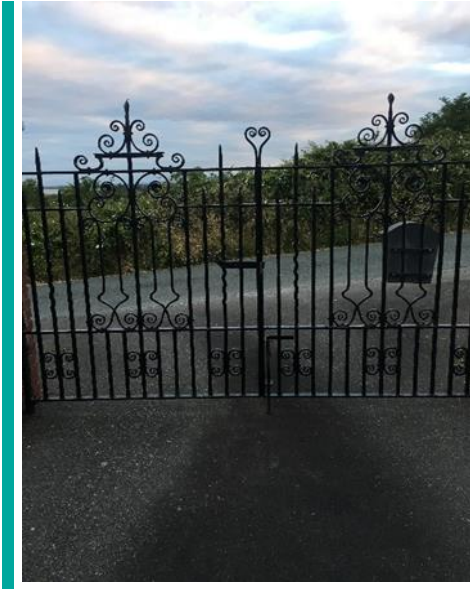
“When I had college from home, rather than adhering to someone else’s schedule, it was planned entirely around when it suited me. It also cut out all the small bits of exercise and last-minute rushes to do stuff that would typically affect my blood sugars over the course of the day”. Rather than walking to college twice a day, I'd be doing all in one stint where I had an hour to prepare and I could change the times depending on how my blood sugars were, so I found it a lot easier” (P4).

The reduced pressure to socialise and removal of the option to eat-out in restaurants was acknowledged as a factor which aided self-management.

“We didn't have the option of eating out in restaurants... maybe it helped things to be better managed because you were just focused on being at home. You weren't socializing, there was none of those aspects like coffee and buns. There was just what you cooked at home yourself. I suppose you had a lot more time and no pressure to socialize” (P8).

One participant felt the management of her diabetes had “*totally changed*” (P9) during the pandemic as she received insulin pump training over Zoom and initial pump consumables were posted, which contrasted to a lengthier approach pre-Covid.

Although participants flagged how Covid-19 had created situations which supported their self-management, the pandemic also created unfavourable conditions. This included increased levels of stress associated with situations arising from lockdown measures such as social isolation, the restrictions on exercise, closure of nursing homes with an inability to see relatives, and less control over day-to-day activities like cooking; “*I found that to be restrictive because I'm used to being in control of what we eat and cook*” (P8).



Covid-19 disrupting self-management routines

“There was that sense of isolation and lack of human interaction. I would go for walks in the garden for 15 minutes. It was a bit like a prison yard. That sort of thing really impacted on my daily routine in terms in of self-managing my diabetes but, I mean, with modern technology was still able to contact people” (P3).

Embracing the potential of online health services and appointments

Three participants who had attended DAFNE online during Covid-19 felt it was beneficial. However, one person was concerned that few people appeared to be accessing the remote course.

“I found it [DAFNE] really good, I was very happy to do it online. During the Covid-19 pandemic I was involved in a lot of training that was moved online and I felt like there was a lot of resistance from healthcare providers to do it online and I just couldn’t understand that... I was surprised when I did the course (DAFNE) online that there were so few people doing it. There were three of us in total and I thought ‘Oh My God there’s hundreds of people waiting to do this course’. You could have 50 or 100 people on here online, people from all over the country” (P10).

Similarly, participants spoke of the benefits of online appointments more generally (for example, less delays) and the need for the health system to continue to embrace this approach. Some reflected on the convenience and “*calm environment*” (P1) of online appointments during the pandemic which “*meant [they] didn’t have to drive for an hour and then an hour back again*” (P6). Two participants who had not been able to access online appointments, felt they lost “*a certain amount of connection*” (P8) when their appointments were moved to telephone calls, suggesting that services perhaps could have embraced the video call more.

One participant faced long delays with obtaining appointments throughout the pandemic and a lack of appropriate support. After not being able to attend their appointment due to being a close contact, they were not offered an online appointment but instead received a date for the same appointment 12 months later.

Vulnerability, fear of Covid-19 and desire to avoid hospitalisation

Some participants expressed fear and a sense of vulnerability during the pandemic, commenting on the goal of “literally trying to keep yourself alive and well and out of medical services” (P8) and citing the “extra stress knowing that you’re medically vulnerable having an underlying condition” (P10).

One person felt the lack of support was propagated at a national level:



Vulnerability and lack of support at a national level

“At a certain point, the narrative changed around Covid and it’s kind of like everything has gone back to normal and you don’t need to wear a mask or socially distance anymore but the medically vulnerable still need to protect themselves because no-one else is going to. Society at large has stopped protecting more vulnerable people so now it’s up to us to keep getting vaccinated, keep wearing masks, stay isolated and everybody else can go off and live normally” (P10).

Feeling vulnerable during the pandemic was also discussed by one participant in the context of the ongoing concern about supply issues which prompted them to stock up:



Administrative burden of supplies during the pandemic

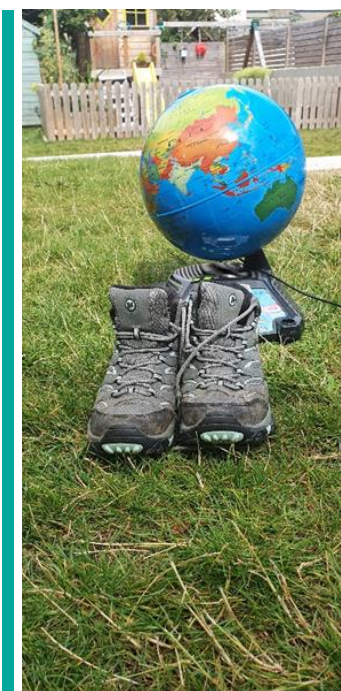
“It’s a full-length wardrobe of supplies and essentially you have to be ready for everything, especially when COVID first hit. You’re hearing about supply chains and your insulin not being available, your needles not being available, and they’re real realities. I don’t want to say I overstocked, but I was certainly being very cautious and maybe ordering unusual amounts and trying to use less at the start...I know there’s a kind of journalistic hysteria, but it does sit with you and go, I’m going to die if I don’t have this stuff. There’s just such an administrative burden around diabetes. I think Covid more so prompted that because people were trying everything to not end up in hospital and you’re kind of calculating the months you’ll have for survival if anything happens.” (P8).

Experiences of the DAFNE programme

Three themes related to experiences of DAFNE: (a) Flexibility and freedom, (b) Access to the DAFNE course; frustration and empowerment, and (c) Application and workarounds.

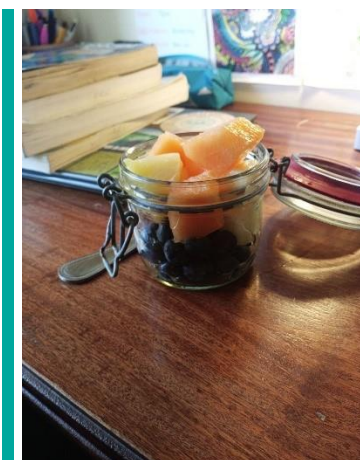
Flexibility and Freedom to engage in exercise and make dietary choices

A core mission of the DAFNE programme is to provide participants with the knowledge and tools to enable them to plan their meals and adjust their insulin accordingly to promote flexibility and limit restrictions. Many participants felt DAFNE provided them with the knowledge and confidence to engage in hobbies and experiment more with their dietary choices.



Flexibility and freedom to make dietary choices

“Just to be able to have the freedom to take that [6 month] trip the following year after my diabetes diagnosis, I felt very free that I could do that...I felt very lucky, and I really feel that if I hadn't done DAFNE at that stage I definitely wouldn't have had the knowledge to allow me to just take off and know how to manage things...DAFNE isn't restrictive on what food you have to eat, and it helped me venture out there and give things a try as well” (P1).



Flexibility and freedom to make dietary choices

“I think when I became a diabetic, everybody said Oh you don't eat chocolate, you don't eat sugar, you know, whereas DAFNE gave me structure. It explained foods that I could eat and the result of what happens when I eat them. You can eat chocolate, it's just three hours later you're going to have the effect. It explains how different foods work. It gives a structure in your life that you can follow...I was never restricted with DAFNE. It gave me more options and helped to explain how to manage my diabetes. So, it gives you freedom again” (P6).

However, one person found the course to be quite restrictive with a lack of flexibility to accommodate personal circumstances and different lifestyles. For example, they flagged the potential unintended consequences of strict carb counting for people with eating disorders, suggesting that the course needs to be better tailored to cater for different individuals i.e., they can avoid the sections which may be harmful.

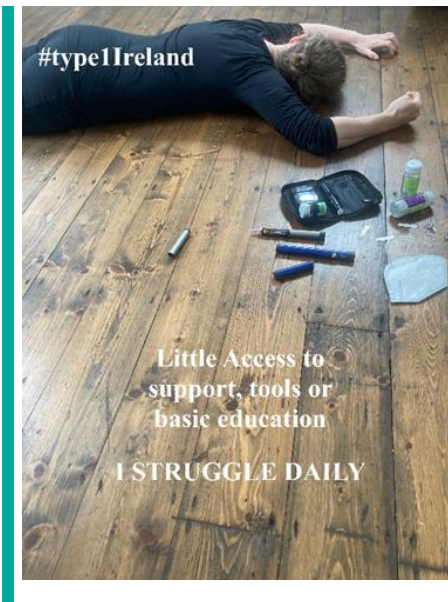
“[I think the core issue with DAFNE, is that it assumes you're a 35-year-old who works at an office job and goes to the gym for three hours a week. That is the assumption and that is the foundation that the entire course is based on, that you're going to be eating premade supermarket food and going to the gym where you can sit down and get back up, and you're not going to be doing exercise throughout the day because those are the things we care about” (P2).

Access to the DAFNE course; frustration and empowerment

Participants expressed frustration with issues accessing DAFNE and yet a sense of empowerment after gaining access to the programme. Those who waited longer (> 5) years spoke of burnout and anger at having diabetes.

Participants felt the course was essential, and the struggle faced by people with T1DM when trying to get access to basic education and tools to allow them to self-manage their condition was highlighted by a number of participants. One participant, who had only accessed DAFNE after more than 30 years living with T1DM, mentioned that they had received no training in diabetes “*other than what they give to a [young] child*” (P4). One participant was frustrated with having to complete a full DAFNE course despite having prior experience of carbohydrate counting, while another was frustrated having to switch to an alternative structured diabetes education programme after returning home from living abroad because DAFNE was not offered in their hospital.

I'm all for structured education but I had to attend five days in person. I'm self-employed. I also had a young - ish child...and I did find the five days altogether a bit much. I had done carbohydrate counting before because I'm diagnosed a long time and I would have thought for someone in my position who also is interested in self education, that a refresher course rather than a full course would have done. There are a lot more people who would benefit out of it than I would...Now with in-person DAFNE programmes there's a long waiting list, 5 days in person – if they offered it remotely, they could get through a lot more people. I appreciate that remote education may not be the best approach for all, but educators need to take the view of people with diabetes into consideration” (P9)



Frustration with access to diabetes services

“It feels like so much energy has to go into the convincing medical professionals that you need support and tools like basic diabetes education, CGMs, a pump. There’s this sense that you should be happy that you’re on the waiting list but being on a list for years doesn’t improve my HbA1c in any way. The narrative needs to change. It shouldn’t be the patients trying to convince the consultant that these things are necessary when everyone knows that they improve quality of life and prevent complications. For me living with type 1 diabetes, it’s a daily struggle - there’s no break from it.” (P10).

After attending the course some participants felt empowered commenting how the programme “*gives you ownership of your disease*” (P1), describing it as “*a God send*” (P4) and “*total lifesaver*” (P4) saying that DAFNE was “*badly needed*” (P4) and “*saved [their] sanity*” (P4).

For one participant, online training enabled her to work-around some of the challenges with accessing to diabetes-related care:

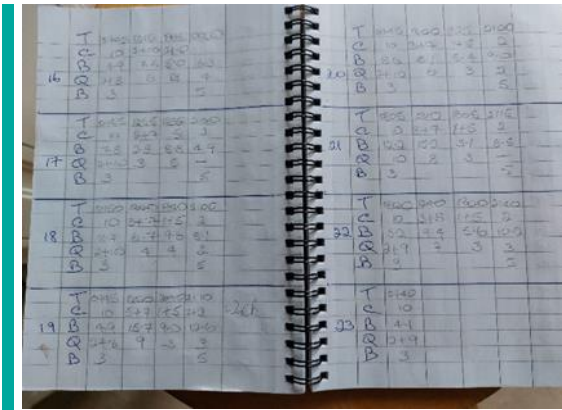


Accessing diabetes services: workarounds

“I got trained on my first pump during Covid over Zoom. I had the support of my [clinical] team during this period, but it was patient led – my team perhaps weren’t happy with how quickly I went live with insulin on the pump but that was my choice. There were a few of us progressing through DIY looping at this stage all over a WhatsApp group and this peer led support was fantastic. So that is the context of the gate; there are possible ways to manoeuvre around a closed gate – unfortunately in Ireland you have to push (perhaps even shove) that gate to open it and it needs a person with a certain tenacity/doggedness/determination to actually open it and not all people have that ability (P9).

Applying and adapting programme principles

Participants provided an insight into how they applied the programme principles into their lives, both in terms of diet and exercise, while also reflecting on the need for workarounds. One participant described the process of calculating and recording insulin doses based on carbohydrate counting and adjusting for exercise in a self-designed notebook:



Applying the programme principles

“I designed this book myself with the dates down the left-hand side and the times that I take the readings going along the top...I transcribe the notebook data onto an Excel spreadsheet, a portion of which I print out and discuss with the diabetes team at clinic. The activity I undertake between BG readings has a significant bearing on how I manage my diabetes and making allowance for this is particularly challenging” (P7).

Most participants found that the programme covered exercise well and gave them the knowledge and confidence to apply the learning in everyday life to be able to engage in more exercise and hobbies. One participant who had waited over 13 years to get access to the DAFNE course, explained the value of this guidance on exercise; they had completed a hiking trip pre-DAFNE course which was “*really difficult*” due to “*constantly having hypos*” From their perspective, the experience would have been much easier if they had access to the DAFNE resources about adjusting their long-acting insulin for different exercises at the time (P10).



Applying the programme principles

“With the DAFNE programme, I was able to manage hiking and was able to regulate coming up and down. This is something that I wouldn’t have been able to do as much when I became a diabetic. It would have had a massive impact. I wouldn’t have been able to do it as easily...I can now do a solid hour’s walk or two hours and I’m not going to fall down and go into a coma or something like that” (P6).

However, some participants had varied views on the way in which the DAFNE course prepared them for managing blood glucose while exercising. For example, one person felt the course “*covered exercise well*” (P7) but acknowledged that “*every individual is different, so it comes down to trial and error*” (P7). Another felt that the course focused more on concentrated periods of pre-planned exercise which they felt “*isn’t realistic for some people*” (P2). The issue of tailoring the course information to cover different types of exercise also arose. One individual commented that the DAFNE programme explained that different types of exercises have different results; “*So, a walk will bring your sugars down but if I went weightlifting, it would bring my sugars up*” (P6) – knowledge of this allowed them to modify the insulin they were taking. However, another individual felt that that the information provided on exercise was “*a major*

shortfall of the course” (P2). They felt that people would benefit from more information about how different exercises would affect individuals’ blood sugars.

Participants also differed in their views on the ease with which the programme principles can be applied in everyday life in terms of both diet and exercise. For example, one individual felt the ratios were “so simple” and “easy to apply” (P1), while others highlighted how time-consuming and stressful stringent carbohydrate counting is and the difficulties associated with performing the calculations.



Carb-counting: stressful and time-consuming

“This is one day out of this diary that I kept for the first few weeks after the DAFNE course. It would just make my day really stressful. They said this should take the stress out of your life, but I still have to walk and now I have to spend half an hour writing it down and figuring out how it’s going to affect me rather than just tossing a glucose syrup forever and saying it will be fine” (P2).

This led to people using guesstimates as a workaround once they became more familiar with the carbohydrate content of regularly eaten food; “It’s a bit of a chore and if I were to apply it [The DAFNE carbohydrate counting technique] diligently, I don’t think I’d have a minute to spare in the day to be honest, so I take a guess here and there” (P7). This participant acknowledged the benefit of the approach, however, recognising that although DAFNE has “added a lot of work”, it has also “taken away a lot of restrictions that were there before” (P7).



Adapting the programme principles

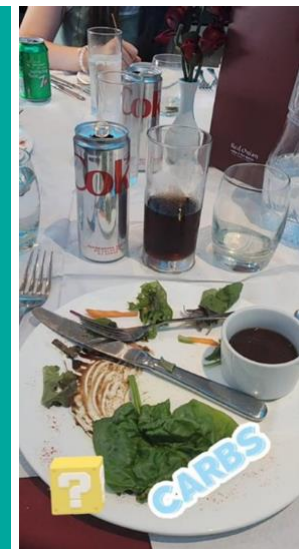
“For a person with diabetes, like everyone else you have to eat, but we have to measure everything. If I’m at home, I use a weighing scales. I would use that weighing scales every day for the past 17 years. Part of the DAFNE programme was showing us food and letting us guess the carbohydrate portion. A big part of the DAFNE programme was to help you when you were, for example, out visiting somebody or out having a meal outside and you can’t really take a weighing-scales out of a bag. I still use the rule of thumb 17 years later. It’s guesswork really, but you do learn over time. Your blood sugar levels will tell you if you underestimated or overestimated” (P3).



Adapting the programme principles: Guessimation

"This [photo] is about guesstimation and the way I wouldn't accurately carb count, but I would take guesses. That's one of the advantages of DIY looping...I don't enter any carbs or any insulin. I let the pump and algorithm do it all for me. You do need to have some DAFNE education to be able to do that and access to technology, but I think a common feature of people living with type 1 diabetes is guesstimation. Maybe I'm different, I know a few people who weigh out and calculate everything but that is not my experience at all" (P9).

The limitations of the programme's carbohydrate counting resources were also acknowledged with one participant describing them as *"more of a hazard than anything else"* (P2) commenting that the resources were limited in the sense that some foods, particularly homemade meals are difficult to apply the resources to.



Applying the programme principles

"The carbs and cals app is brilliant but I suppose you're still doing essentially a bit of guesswork. This particular evening, I was out for an Indian and I went very low afterwards. I've had diabetes since I met my husband and I consider him to be very educated, but I remember him saying "You've had a big meal, how were you so low" People often don't understand that if you're taking, between 12 to 14 units for example for a meal, one unit is the difference between coasting along at a very nice 5.5 or being a 2.5. Sometimes it's not worth eating out in restaurants because you have a lot less control" (P8).

Other forms of support for type 1 diabetes

Themes that did not strictly fit into the first two domains were (a) The role of technology, (b) Support or lack of support from others and (c) "You don't get a holiday from it".

The role of technology

The positive role that technology plays in assisting self-management of T1DM was captured by a number of participants in their photos.



Positives of using technology

“I’m definitely a technology person so when they gave me the option of switching to a pump, I was all for it and wanted to learn about it. What I liked is that when I first got that glucometer, it was connected to everything. So, my blood sugars are connected to my Apple Watch and all the technology is looped together. I can look at it straight on my phone. It makes it all kind of easy. I find that really compact to carry as well. That was one of the things when I first became diabetic, the thought of having to carry all this equipment with me, but I just find that stuff is so neat and small now, it can be just invisible” (P5).

The benefits of technology such as Dexcom Continuous Glucose Monitoring (CGM) were flagged; being able to see real-time updates in blood sugar levels, as well as the discreet nature of the device.



Positives of using technology

“The Dexcom has been a major life changer for me. I put a transmitter on my arm every 10 days, and it’s connected to a server, so my clinic is able to review my blood sugar levels. More importantly, it is connected to my phone so it’s able to tell me on a real-time basis 24/7 what my blood sugar level is and how it’s behaving within the parameters that I’ve set for it...That’s the transmitter on my arm. It’s very discreet, nobody sees it, although I see people walking around all the time with them stuck in their arms. It’s a fantastic device” (P3).

Participants highlighted the issues with accessing technology, including perceived ageism. *“Diabetes technology is so amazing, we’re at the cutting edge, but the reality is very few people have access to it”* (P10). This participant felt that the *“totally normalized ageism in services and care”* (P10), was a significant barrier faced when trying to access this technology (e.g., pumps). Two participants mentioned that they only got access to Dexcom because they were planning a family:



Accessing technology

“I use a Dexcom and that’s been lifechanging. I got that pre-Covid and, in terms of my mental health, it’s been amazing. I was looking at starting a family pre-Covid and that’s the only reason I got Dexcom. Later I was told, “now that you’re not trying to get pregnant anymore you don’t need Dexcom”...I had to stand up for myself, but I do wonder what would happen to people who don’t...I’ve been unwell for months after Covid and I wonder how people would have been able to manage this without Dexcom and DAFNE to be able to see what’s actually happening with your blood sugar. Without it it’s stabbing in the dark essentially” (P8).

A participant who had to leave a career as a health care professional discussed the fact that access to technology such as a Dexcom may have been a deciding factor as to whether to leave or stay.

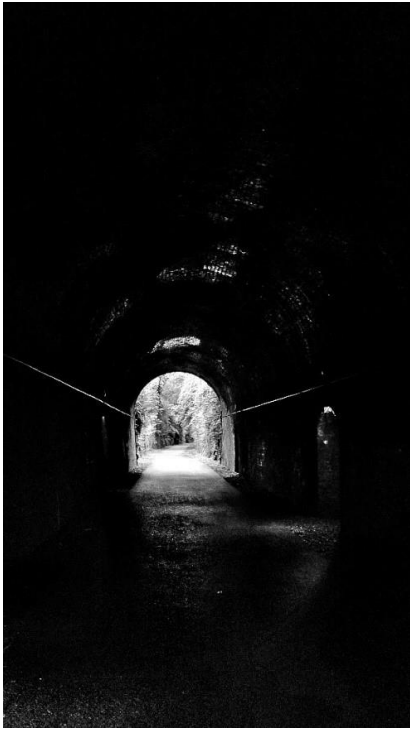
Some participants talked about the limitations of technology; for example, that there is a twelve-hour gap between calibrations on an insulin pump, so they come at awkward times, and that an insulin pump runs on an AI that brings their sugars below seven. This cannot be adjusted to accommodate some individuals’ desires to keep their sugars slightly higher before exercise or strenuous activity to allow for severe fluctuations.

Support or lack of support from others

Support (or the lack of support) from others was highlighted as playing a key part in the management of their diabetes. Support took different forms, be it at work, by friends and family and by the healthcare system and medical professionals.

Diabetes in the workplace: Hidden or supported?

Participants had mixed experiences when it came to being supported by colleagues and bosses at work. The level of support that they received impacted on the management of their diabetes. For example, those who had to hide their diabetes, in particular hypoglycaemic events, at work, felt anger and burnout.



Hiding diabetes in the workplace

“The tunnel is about hiding hypos in work”. The DAFNE crew kept telling me to insist on having a planned workday, but my boss kept insisting that it wasn’t possible to give me a planned workday...I needed this so that I could estimate my insulin doses for the day. I used to have to hide my hypos. Not all employers are supportive of diabetics, and it is harder for diabetics to get jobs as well. These are things I want people to know... Low blood sugars can be deeply scary: I've had a few in my last job where it felt like my body was going through a heavy tunnel, I'm barely able to be anything in this tunnel's weight, I'm bones made from air, I'm nothing more than this. I didn't want anyone to notice my 'not working' and I didn't want to give them a chance to throw a song and dance about me having low blood sugar. To them low blood sugar is so simple to solve, a bar and a coca cola and it's cured. They never tried to understand why I wanted to avoid the lows” (P4).

Two participants reflected on having to give up jobs as a result of their diabetes and unsupportive work environments. Another worried about their colleague’s perceptions when they had to take time off to go to appointments. One person mentioned the fact that they had used up three annual leave days already this year on attending appointments, suggesting that this feeds into *“already increased levels of fatigue [about diabetes]”* (P7).

Some participants appeared to mask diabetes at work regardless of the level of support offered; for example, one explained that, while they had disclosed their diagnosis to a few colleagues for safety reasons, they preferred it to remain unknown:

“I didn't want somebody to look me and go ‘Oh, you're a type one diabetic’. I just kind of want it to be invisible as well, the invisible disease” (P5).

Not all participants had negative experiences with diabetes at work with one commenting how they had *“tremendous support”* (P6) from their workplace and were given time off to do the DAFNE course.

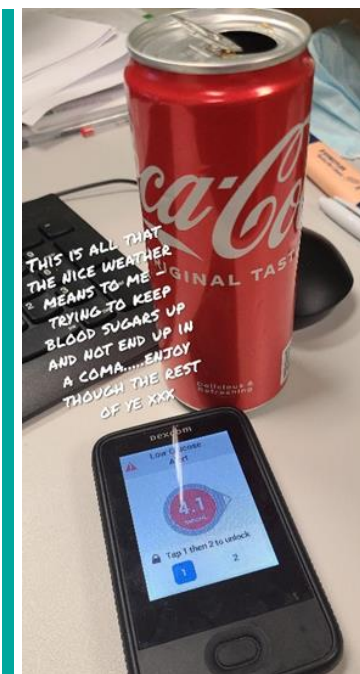
Support or lack of from health professionals, family, and friends

Participants also highlighted the support (or lack of) from health professionals with one describing diabetes appointments as *“box-ticking”* (P10). Some participants explained they had not been asked about their experiences with managing T1DM before, *“I never get to talk about this kind of thing with anyone”* (P4), appreciating the opportunity to share their thoughts; *“It's [this project] the first time I've been asked my opinion on what it's like to*

have type 1 diabetes. No clinical staff have ever asked me that question” (P10). One person suggested the need to implement psychological support in routine T1DM care:

“You go to appointments and people say; ‘how is your HBA1c?’, but in 10 years only one clinician has ever stopped to say; “but it’s hard though and how are you mentally”? Even during covid it was a case of “did you get covid, are you vaccinated?”, and not an acknowledgement that it’s been hard. Obviously, the physiological elements and those parameters are hyper-important but when your mental health is down and you feel that people don’t care, that leads to fatigue, and you start to feel burnout. If people don’t manage their condition, they’re going to be a burden and if the HSE don’t put in some kind of psychological support around type one diabetes there’s going to be huge issues”. (P8).

In terms of family, friends and the wider public, one participant also highlighted their desire not to burden family/friends with their diabetes but used humour to subtly remind family of their condition. The importance of educating the wider public about how to support people with T1DM was raised by one person, commenting that people without diabetes are “really scared that you’re going to have a high glycaemic reaction faint or go weird on them” (P3).



Support from family and friends

“My Family and friends are great and supportive with a lot of things, but no one wants to hear you complain all the time. People get burnt out very quickly so I’m conscious not to say too much about my diabetes. I send these kinds of messages to my family and friends from time to time to remind them that I’ve a lot going on, but they’re not digs. I use humour to minimise it because you don’t want to be that complainer” (P8).

One participant described their dog as a source of support:



Support from other sources

“He’s 17. He’s been amazing. He has been my lifesaver. I got him around the time I did DAFNE. I started walking a half a mile every few days. He used to notify me of my hypos by touching my knee. This was before Dexcom. He used to tip my knee with his nose to let me know my blood sugars were going low. He’s been a great little guy. He’s untrained, just protective” (P4).

“You don’t get a holiday from it”.

Participants spoke about experiencing burnout from the time-consuming and constant nature of self-management (which fed into anger at having diabetes), the physical and mental impact of diabetes, and the lack of escape, having no ‘days off’. One participant felt it was easy to be knocked off track while self-managing their diabetes and alluded to the *“impossibility of balance”* in daily life (P4).

One participant explained the physical and mental toll associated with T1DM, that they had seen changes in their health pre and post diagnosis, including their physical health. They experienced a sense of *“helplessness”* (P10) in the face of such deterioration in physical health coupled with a lack of support.

“When I was diagnosed, I was fairly healthy. I was quite a sporty person. I was into triathlons and doing lots of different things. I just feel that being diabetic has so negatively impacted my health and that that’s not fully acknowledged, you know. I wish someone had said to me in the beginning that this will have a serious impact on my health it has to be taken really seriously... I have lost almost two thirds of my hair and I don’t have the same energy I used to have. I feel unwell a lot of the time. You share this at meetings when they’re on and it feels like it’s just not taken seriously even though it’s directly related to type 1 diabetes” (P10).

This participant, commenting on the lack of adequate support, flagged the *“problematic”* (P10) framing of some research; there can be a tendency to frame young adults with T1DM as *“this really difficult population who don’t want to engage in clinical visits”* (P10) without acknowledging the reasons why some individuals don’t engage with health services:

“The support isn’t there. Why would people engage with that [service]? It’s put on the patient. If you don’t have good HbA1c it’s because you don’t try hard enough and you’re obviously non-compliant but that just isn’t true. A lot of people just don’t know what they’re doing, are trying really hard and are completely burnt out. That’s the reality. It’s not that they’re this difficult population who don’t care about their health. It’s quite the opposite. It’s people dealing with burnout and not knowing what to do or how to manage things. There just needs to be better education and more input” (P10).

Participants also used their photographs to communicate the need for escapism and the lack of days off from diabetes. The all-consuming nature of diabetes was summed up by one participant: *“As a person with diabetes you’re always conscious of it. You don’t get a holiday from it”* (P3).



The need for escapism

“I was down by the sea and decided to take a picture because I use it as a switch-off from diabetes and I forget about everything. I have suffered from burnout where I don’t want to be diabetic anymore and I don’t want to do this which comes in cycles. The beach is at my doorstep and it’s where I can switch off and I don’t think about how many carbs I have to count because for me diabetes can be all-consuming” (P5).

Discussion

Summary

Structured diabetes education aims to enable people with T1DM to develop the knowledge and skills to enable participants to better manage glucose levels and improve their quality of life. The success of structured education programmes such as DAFNE depends on the ability of participants to integrate learned self-management behaviours into daily routines (11, 12). We aimed to explore experiences of the DAFNE structured education programme including the process of applying the programme principles in everyday life, as well as experiences of managing T1DM during the Covid-19 pandemic. In terms of experiences of DAFNE, participants highlighted the flexibility and freedom afforded by programme and the sense of empowerment following the course. However, there were mixed experiences of applying the course principles (for example, carbohydrate counting) to everyday life; some found it easy while others

felt it was time-consuming, stressful, and difficult. Participants felt the content and format of the DAFNE programme needs to be better tailored to suit people's needs and different lifestyles. A number of participants expressed frustration after experiencing a long delay to access the DAFNE programme. In terms of their experience of Covid-19, participants felt particularly vulnerable during the pandemic, which both disrupted self-management of their diabetes but also supported it. Those who attended online medical appointments during Covid-19, felt that more health services, including DAFNE, should embrace this format to shorten wait times and improve access. Lastly, participants discussed other forms of support for type 1 diabetes, highlighting the important role of technology, the support and lack of support from others in their lives, and the all-consuming nature of diabetes and associated burnout. We discuss these findings in the context of published literature, before discussing the implications of the findings and how they may inform the delivery of the DAFNE programme and ways to support the T1DM population in Ireland.

Comparison with other studies

Similar to previous studies (20-29), we found that people with diabetes experienced increased stress due to fear of Covid-19 (21, 37), restrictions on socialisation and engagement in outdoor activity (22) as well as reduced control over daily routines such as grocery shopping and work (21, 22), all of which participants felt negatively impacted self-management. Our findings also indicated that some aspects of Covid-19 and the resultant 'lockdown' were conducive to T1DM self-management, which may help to explain why previous studies have observed increased glycaemic control among people with T1DM throughout the Covid-19 pandemic (27, 28). These factors included increased use of telemedicine and other online health services, a slowing of daily routines allowing for more time for meal planning and precise carbohydrate counting, a reduction in workplace related stress for many individuals, and more control over dietary habits due to restricted opportunities to eat out in restaurants and less pressure to socialise.

The need for the healthcare system to continue to embrace online health services was highlighted by participants. Many reflected on the value of online videoconferencing for T1DM appointments in terms of convenience, reduced cost, and the role these services can play in shortening waiting times and facilitating timely access. However, one participant felt a loss of connection when their appointments were switched to telephone calls instead of video calls. The Covid-19 pandemic has focused more attention on remote health services including telemedicine and online education programmes, providing an opportunity to expand this infrastructure (38). Findings from a global survey (n=7277) directed at individuals with T1DM distributed in 89 countries on an open-access platform between March and May 2020 suggest that telemedicine is an effective method of providing care and support to people with T1DM as most visits revolve around review of data from connected devices such as Dexcom and a discussion of therapy options and self-management habits (39). This global survey highlighted advantages associated with online visits that are consistent with our findings, including the potential to minimise the cost, time, stress, and inconvenience of attending appointments which is a particular burden on individuals with chronic illnesses (39). However, the limitations of online health services have also been acknowledged, including the inability to carry out a proper physical exam, internet connectivity issues, lack of online infrastructure across some services, difficulties with use of technology

among some patients, and the lack of face-to-face interaction which may impede the ability of healthcare providers to build rapport with their patients (40).

This research reinforces and builds upon the findings of other qualitative DAFNE studies, offering further understanding of the factors which support and hinder the ability of people with T1DM to assimilate DAFNE learning in everyday life (13, 17, 18), as well as the behaviours involved in sustained self-management (19). Potential barriers to the application of programme principles in everyday life identified in the current study included the time-consuming nature of stringent carbohydrate counting and the lack of tailoring of course content. Enablers of diabetes management included timely access to the DAFNE course, access to technology such as CGM and insulin pumps, and support from health professionals (including psychological support to manage burnout), family, friends, and colleagues. The latter aligns with previous research which suggested that the level of support received from other sources as well as experiences of burnout influence whether people with T1DM and other chronic diseases adhere to self-management principles (17, 18, 19).

Implications

There are four key implications arising from this research. First the DAFNE course should potentially be tailored more to fit individuals' lifestyles and what they need from the course. Second, there is potential for additional support to be provided to graduates of the programme, including psychological support, support via peer networks, resources on managing burnout, and providing information which participants can bring to employers about how to support the needs of someone with T1DM in the workplace. Third, to address access, DAFNE and the wider healthcare system should endeavour to embrace a hybrid delivery. More resources should be made available to individuals with T1DM and their families upon diagnosis to provide support to individuals who do not have timely access to the course.

Tailoring the DAFNE programme to facilitate the application of the principles in everyday life

Participants in our study had differing views on how DAFNE principles could be integrated into daily life. One issue flagged was the need to tailor the course to suit individuals' needs. For example, adapting the course *format* so that it is a flexible resource, allowing individuals can engage with sessions they feel they need (such as carbohydrate counting or managing exercise) based on their prior knowledge, experience and/or personal circumstances, without having to do the entire course over five days. This model could be used for refresher training. Offering a potentially shortened version of the DAFNE course and an ongoing online option would also facilitate people who cannot commit to the full course or an intensive week-long in-person course due to work or other commitments, to avail of the course. One participant felt certain elements of the course *content* should be more personalised, for example the section on controlling blood sugars while exercising, so that they could better tailor the advice to their own lifestyle and hobbies.

Providing additional support to graduates of the programme

Psychological support could be integrated into routine T1DM care from diagnosis to address challenges discussed by participants in terms of coping with the diagnosis, adjusting to daily life post-diagnosis, and managing burnout. The DAFNE programme could play a pivotal role by embedding psychological support and/or offering some resources to patients on managing burnout. The value of peer-led support was recognised by participants. To complement this, a peer support network could be embedded in the structure of the DAFNE programme. More support also needs to be offered to individuals with T1DM in a workplace setting; DAFNE could play a role in leading this change by providing resources that graduates can bring to their employers with advice on how to support their needs, for example, working with the employee to plan their schedule in advance so that they can adjust their insulin accordingly.

Addressing access: Providing more resources and embracing hybrid or online DAFNE

Our findings also highlight the need to improve access to T1DM information at diagnosis as well as access to the DAFNE programme, an issue which continues to be flagged nationally; in March 2021 there were 713 people on a waiting list for DAFNE education (41). The Covid-19 pandemic has highlighted the value of a hybrid model of care which incorporates online and in-person services (42). In response to the Covid-19 pandemic, some DAFNE centres offered remote DAFNE programmes comprising of a blend of online learning, workbook activities and remote group sessions facilitated by DAFNE educators. Participants in our study who completed the remote course found it more convenient and accessible, suggesting DAFNE centres should consider continuing or starting to offer access to the programme online or as a hybrid model. More resources should be made available to individuals with T1DM and their families upon diagnosis in the form of online materials and educational videos for self-management to provide support to individuals who do not have timely access to the course.

Strengths and limitations

To our knowledge this is the first study to use photovoice to explore the experiences of graduates of the DAFNE programme. Engaging in the photovoice method facilitated collaboration between researchers and participants and offered a platform for participants to discuss their experiences. As the method prompted participants to illustrate their experiences, we feel it contributed to important and more illuminating insights. The photographs were used to guide interviews, which as a result were largely participant-led, enabling participants to discuss aspects of their self-management experiences they felt were most meaningful to them and most important to share.

To recruit participants, we asked DAFNE educators known to the team via another project to act as gatekeepers. As a result, we do not know how many people were contacted or the characteristics of people who did not participate. Although there are 11 DAFNE sites established nationally, recruitment was limited to a four DAFNE sites where we had established connections. However, recruitment was also conducted via social media, and the group of participants recruited through this avenue differed in terms of geographical location, gender, and date of completion of DAFNE.

We recognise that participation in this study was time-consuming which may have discouraged participation by people who were unable to commit to all three elements of the study (initial online briefing session, taking photographs over a ten-day period, and engagement in an interview guided by their photographs). The briefing session and interviews were held online via Microsoft teams for convenience as participants were geographically dispersed, however this may have discouraged participation by people who were not comfortable with using technology. In line with ethical guidance for photovoice research (30), participants were provided with consent vouchers and instructed to obtain consent should they capture other people in their photos. This may have curtailed photograph opportunities as participants may not have felt comfortable approaching strangers and obtaining their consent. Nonetheless, this is a common concern in photography for research (30).

Another potential limitation is that the number of photos and the extent to which people discussed them in subsequent interviews varied. This could mean that certain views and perspectives appear more strongly than others. To minimise this, we aimed to include at least one photograph and quote from each participant in the results section. We also gave participants the opportunity to review matched photos and quotes to ensure that they were happy that their views were appropriately represented.

Conclusions

Participants conveyed their experiences of DAFNE and the Covid-19 pandemic through photographs, offering a unique insight that can be difficult to elicit through more traditional research methods. Our findings highlight the strengths of the DAFNE programme including the flexibility and freedom it offers in terms of expanding dietary options and facilitating engagement in exercise and other hobbies and equipping individuals with T1DM with the skills and confidence to self-manage their diabetes. Our research also points to areas where the programme can be enhanced, for example by tailoring the programme content and format, continuing, or starting to offer the programme online to support greater access, and taking steps to embed psychological support and the management of burnout. Our findings relating to the experiences of people with T1DM during the Covid-19 pandemic suggest the importance of telemedicine and online health services.

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