Individualized visual narratives: type 1 diabetes management strategies among three runners in the London Marathon

Narrativas visuais individualizadas: estratégias de gerenciamento da diabetes tipo 1 entre três corredores na Maratona de Londres

Denise Montt-Blanchard, María Teresa Onetto, Raimundo Sánchez

type 1 diabetes, marathon running, visual narratives, diabetes management strategies This study investigates the diabetes management strategies of three high-level athletes with Type 1 Diabetes (T1D) during the 43rd London Marathon. The athletes' strategies, which included insulin dose adjustments, carbohydrate intake, and monitoring techniques, were analyzed using a collaborative autoethnographic approach and data from medical and running devices. The athletes, two males and one female, used various technologies such as Supersapiens, Freestyle Libre, and the Medtronic Minimed 780G insulin pump to manage their diabetes during the marathon. Despite individual challenges, all three athletes successfully completed the marathon. The study presents the strategies, glycemic data, and major highlights using visual narratives, providing valuable insights into the experiences of athletes with T1D during endurance events. These narratives effectively communicate the challenges faced by athletes with T1D and can help optimize diabetes management during endurance events.

Diabetes tipo 1, corrida de maratona, narrativas visuais, estratégias de gestão de diabetes Pessoas com diabetes tipo 1 (DT1) enfrentam desafios no controle glicêmico durante atividades de resistência, como corridas de maratona. Este estudo de caso investigou a experiência de três atletas de elite com DT1 na 43^ª Maratona de Londres, visando otimizar estratégias de gerenciamento da diabetes durante esses eventos. Foram realizadas entrevistas colaborativas com os atletas para compreender suas estratégias de gerenciamento da diabetes, incluindo ajustes na insulina, consumo de carboidratos e monitoramento glicêmico durante a maratona. Dados quantitativos foram coletados de dispositivos médicos e de corrida. Os atletas, dois homens e uma mulher, concluíram com sucesso a maratona, apesar dos desafios da diabetes, utilizando dispositivos como Supersapiens, Freestyle Libre e bomba de insulina Medtronic Minimed 780G. Este estudo demonstra a eficácia das estratégias de gerenciamento da diabetes em atletas de alto nível, fornecendo insights valiosos para melhorar o desempenho durante corridas de maratona. What is already known on this topic: Technological progress aids glycemic control for type 1 diabetes during exercise, vital for highendurance activities. Yet, insights into type 1 diabetes athletes' decision-making during major events, e.g., marathons, are limited.

What this study adds: This research introduces innovative visual aids. By scrutinizing strategies of three runners managing T1D while marathon running with continuous glucose monitoring, it reveals novel approaches to overcome challenges faced by patients.

How this study might affect research, practice, or policy: Findings of this study underscore the urgency to enhance type 1 diabetes education material regarding personalized exercise management, mitigation of risks and safe execution of endurance activities. These revelations can inform future research, guide clinical practice, and contribute to the development of evidence-based guidelines specifically tailored for marathon runners living with type 1 diabetes.

1 Introduction

Type 1 diabetes mellitus (T1D) is an autoimmune disorder characterized by insulin deficiency due to the destruction of pancreatic beta cells (Soleimanpour & Stoffers, 2013). Exercise offers numerous health benefits for individuals with T1D, including increased longevity (Moy et al., 1993), improved insulin sensitivity (Ding et al., 2019), and a reduced frequency and severity of diabetes-related complications (Foster et al., 2019; Stadler et al., 2014). Active adults with T1D often exhibit improved glycemic control, healthier body mass index, and decreased daily insulin requirements (Riddell et al., 2017). Exercise also contributes to overall psychological well-being (Edmunds et al., 2007). However, the acute impact of exercise on blood glucose levels in individuals with T1D is complex and patient-dependent, leading to low physical activity participation in this population (Bohn et al., 2015).

Recently, more individuals with T1D have been pursuing high-level sports (Weiss et al., 2023). Studies show that athletes with T1D can achieve metabolic outcomes comparable to non-diabetic counterparts (Riddell et al., 2020). Technological advancements, such as continuous glucose monitors (CGM) combined with continuous subcutaneous insulin infusion (CSII) in Advanced Hybrid Closed Loop (AHCL) therapy, have significantly improved glycemic control. CGM helps monitor glucose fluctuations during exercise, reducing the risk of extreme glycemic values in athletes with diabetes (Riddell et al., 2020).

During exercise, blood glucose regulation in individuals with T1D depends on factors like muscle glucose uptake, hepatic glucose production, and glucose ingestion (Tagougui et al., 2019). Exercise intensity plays a crucial role, with moderate-intensity exercise linked to a higher risk of hypoglycemia and high-intensity exercise to hyperglycemia (Riddell et al., 2020).

Technological advancements, notably the AHCL system, enhance glycemic control in T1D by mimicking natural hormone secretion (Tagougui et al., 2019). The AHCL integrates a complex control algorithm that analyzes CGM data to determine precise insulin delivery via the pump. The automatic mode (AM) tailors insulin dosages to glucose levels, trends, and settings. AHCL is at the forefront of mitigating exerciseinduced hypoglycemia, offering various insulin programs. A notable feature is the temp target, automating basal insulin slightly above normal levels (150 mg/dL instead of 120 mg/dL) to prevent hypoglycemia (Oishi et al., 2018). Patients also have the option of personalized insulin infusion using the manual mode (MM). This technology significantly contributes to improving diabetes management during physical activities.

Exercise can significantly impact CGM system accuracy, complicating therapeutic decisions (Yardley et al., 2013). Factors like excessive sweating, elevated skin temperature, and mechanical stress during physical activity can lead to discrepancies between CGM readings and actual blood glucose levels. Additionally, interference with other communication devices and the use of mobile devices near insulin pumps may disrupt CGM transmission during activities like marathons (*System User Guide. MiniMedTM* 780G, 2022). When CGM transmission is lost, the AHCL system employs a non-modifiable automatic function called "safe basal," delivering a constant insulin rate based on the patient's insulin history to cover basal needs. It's important to note that safe basal doesn't adjust insulin delivery based on CGM data. Therefore, strategies to ensure the reliability and accuracy of CGM systems during exercise are crucial and should be implemented.

As technology generates real-time data that requires interpretation by both patients and caregivers, because effective visualization technologies have the potential to transform raw data and the outputs of complex computational models into actionable insights that improve patient care (Gotz & Borland, 2016), it has become common to frame medical information within a narrative context, aiming to enhance comprehensibility (Mittenentzwei et al., 2023).

In addition, individuals often resort to storytelling as a means to comprehend their afflictions; by contextualizing their illnesses within narratives, they often discover a path to healing (Frank, 2004). The concept of quest narratives, as articulated by Frank, underscores this process of transformation, where the act of narrating illness facilitates a journey towards personal reinvention (Frank, 2006). Drawing inspiration from this framework, the present case study embraces the idea that weaving quest narratives can serve as a potent approach for constructing the narratives surrounding the subjects under examination.

Narrative visualizations shift the focus from data analysis to presentation, with a focus on comprehensively presenting disease aspects within a story. Characters play a pivotal role in data-driven disease stories, involving at least one character, whether human or an object like an organ or disease (Meuschke et al., 2022). These characters can be protagonists, generating user empathy, antagonists opposing protagonists, or supporting characters aiding the protagonist. However, the impact of characters on user engagement and trust remains relatively unexplored (Mittenentzwei et al., 2023).

Managing diabetes during athletic training and competitions is challenging, with research aiming to optimize glycemic management for high-level athletes with T1D (Tagougui et al., 2019). Field studies have explored insulin-dependent individuals completing endurance runs, including marathons (Cauza et al., 2005; Oishi et al., 2018) and ultramarathons (Weiss et al., 2023), using technology devices. Yet, integrated data on glycemic control and diabetes management strategies for marathon runners as a visual narrative is lacking.

Through analytic autoethnography (Montt-Blanchard et al., 2022), this report presents the marathon experiences of three T1D runners. The objective is to highlight challenges faced by high-level athletes with T1D and offer insights for healthcare professionals to optimize patient care and support endurance pursuits. Specific report goals include describing patient glycemic control and characteristics, analyzing diabetes management strategies pre- and during races (including insulin adjustments, carbohydrate intake, and monitoring), presenting the design process for a visual narrative capturing the experiences of these three patients, and discussing the implications of these visual aids for patient care. This discussion focuses on lessons learned, potential enhancements in diabetes management during endurance events, and the importance of individualized strategies for T1D athletes.

2 Study methodology

2.1 Participants

This study involved three participants aged 18 and above, comprising the primary autoethnographer and two secondary runners, all diagnosed with T1D for at least five years. Participants were categorized as medium and advanced runners based on their training volume and weekly training, in line with Besomi et al.'s framework (Besomi et al., 2018). They had all successfully completed the 43rd London Marathon in 2023, representing the culmination of their rigorous training and diabetes management efforts. Recruitment was facilitated through Marathon Charities, Diabetes UK, and Supersapiens. The observational study, conducted in 2023 and approved by the Social Sciences Ethical Committee at the Pontifical Catholic University of Chile, obtained informed consent from all participants for interviews and data analysis. Given the exploratory and qualitative nature of the study, the sample selection process followed an emergent approach (Cohen & Crabtree, 2006).

2.2 Methods

This study embraces a patient-centered design approach (Ku & Lupton, 2020), prioritizing meaningful and empathetic user experiences that cater to patients' needs and aspirations (Lewiss & Lupton, 2021). It combines quantitative and qualitative data to gain insights into human behavior. While measurement provides precision, it can lack contextual depth, potentially leading to misguided decisions. Narratives, on the other hand, offer valuable context for understanding decision repercussions but have limitations due to their selectiveness and limited scope (Norman, 2023).

To understand individual experiences in the context of T1D during a marathon race, we employed autoethnography and ethnography methodologies (Xue & Desmet, 2019). These approaches allowed us to delve into the intricate decision-making processes during physical activity. Additionally, we utilized a visual narrative methodology to present a comprehensive and captivating portrayal of the interplay between design, individual experiences, and the unique challenges posed by T1D. This combined approach aims to offer a holistic understanding of the subject.

2.2.1 Autoethnography

The primary adoption of autoethnography as the chosen method is rooted in its capacity for interpretation and its deliberate orientation towards intertwining the researcher's personal encounter with the intricate fabric of cultural and societal dynamics (Holman Jones, 2005) and because it helps scrutinize individual practices with enhanced precision, particularly when delving into the exceptional and infrequent occurrence of running a marathon while navigating the challenges of T1D. The concept of "subjugated knowledge" (Denshire, 2010) inherent in the lived experiences of a marathon runner grappling with T1D provides the researcher with a privileged vantage point to gather information that might be concealed, not readily discernible, or absent within existing literature. Thus, to comprehend individual experiences during a major marathon race within a T1D context, quantitative and qualitative data from the autoetnographer was collected through (i) CGM data downloaded from Carelink platform, (ii) an Athlete Diary (handwritten notes and figures), (iii) running performance data downloaded from Garmin Connect.

2.2.2 Ethnography

Ethnography was employed to enhance the depth of insight into the diabetes experiences of the second person within the context of the marathon, synergistically complementing the autoethnographic viewpoint. As underscored by Atkinson, ethnography entails a profound immersion into the everyday lives of research participants to discern their experiences and contexts, encompassing the analysis of artifacts (Atkinson, 2015). In this study, patient glycemic records obtained from different glucose monitoring platforms as well as running watches served as crucial artifacts, illuminating the intricate journey each patient undertakes to define their personalized strategy. To capture the essence of behavior within naturally occurring conditions, which ethnography inherently (Belk et al., 1988), we enlisted T1D runners as informants. Qualitative data were meticulously amassed through a multifaceted approach encompassing (i) post-marathon dialogues, (ii) in-depth interviews, (iii) exchanges of information via email and WhatsApp, and (iv) supplementary communication materials provided by the subjects, such as power point presentations and podcasts they have delivered.

2.2.3 Visual narratives

Narrative information visualizations strategically employ a fusion of persuasive, rhetorical techniques to effectively communicate intended stories to users, while simultaneously incorporating exploratory, dialectic strategies to empower users with control over their gained insights from interactive engagement (Hullman & Diakopoulos, 2011). In the context of this study, an initial autoethnographic visual narrative was created, integrating essential components synonymous with the construct of a disease story (Holman Jones, 2005):

- **Data-driven**: Constitutes content extracted directly from the amassed data. This dimension encompasses the quantitative data extracted from the glycemic records and running metrics, including pace, calories expended, and time elapsed during the marathon.
- Context-driven: Encompasses content that extends beyond direct data extraction, incorporating common domain knowledge or information synthesized from diverse studies, often curated by domain experts. This facet is represented through elements such as the marathon route, clinical recommendations for diabetes management strategies during exercise, and the autoethnographer's personal encounter.
- Character-driven: Involves content anchored in a tangible or fictitious human character, such as a domain expert or an individual influenced by the focal subject of the narrative, such as a patient. Within this study, the character-driven dimension assumes the form of the runner character and their decision-making journey.

By skillfully merging these dimensions, the autoethnographic visual narrative captures a comprehensive and multi-dimensional portrayal of the intricate interplay between quantitative data, contextual insights, and the human element within the narrative, effectively conveying the dynamic narrative of running a marathon while navigating the challenges of T1D.

In adopting the character narrative approach for this study, we draw inspiration from Robert Kosara's insights into visualization techniques tailored for a broader audience. In the context of our visual data stories, we emphasize the key components of characters, conflict, content, and structure (Kosara & Mackinlay, 2013). Aligning with Joseph Campbell's Hero's Journey (Campbell, 2008), we created a data driven visualization for a patient experience running the London 2023 marathon, the story features: (1) a patient as the protagonist, (2) T1D as a co-protagonist, and (3) no human protagonists. To address the design of the visual narratives for the London Marathon cases, we employed an heuristic framework for narrative visualization evaluation (Errey et al., 2023), defining the design requirements for the visual aid. The first visual narrative was initially presented to the second persons, and subsequent visual narratives were collaboratively developed through a co-creation process.

3 Results

3.1 Design requirements for the visual narrative

Following the heuristics framework for visual narratives by Errey et al. (Errey et al., 2023), we carefully considered the following elements in the composition of our visual narrative:

- 1. *Logical layout*: Our aim was to reduce cognitive workload by employing a logical arrangement of graphical data, using a situated cartography based on the marathon map. This layout allows for the incorporation of additional layers of information within a context that is recognizable to both patients and the general audience. Drawing from typical practices in physical culture, we integrated the runner's route, distance, and time, aligning with established conventions (Sun et al., 2013).
- 2. *Information density*: Recognizing the need for high information density, we adopted a design strategy that compartmentalizes data into distinct segments, categorizing information based on diabetes-related data, running performance, and personal insights. This approach empowers readers to selectively delve into specific details and navigate the visual narrative as desired.
- 3. *Mindful use of color*: We employed a color palette that reflects the affective response in line with clinical consensus for glycemic targets. This choice ensures comprehension and resonance within the diabetes community. The color spectrum was extended to represent fluctuations in glycemic levels over time, covering very above range, above range, within range, below range, and very below range (Battelino et al., 2019), thereby enhancing clarity and understanding.

4. *Textual integration*: Our visual narrative emphasizes an optimistic tone in both text and design, regardless of the presented diabetes control outcomes. Our intention is to provide motivating evidence to inspire other runners with T1D to participate in marathons, fostering a sense of empowerment as observed in patient recovery (Vansteenkiste et al., 2021).

In crafting an engaging reader experience, we focused on the following factors:

- 1. *Cohesiveness*: The visual aid maintains data consistency to facilitate comprehension, drawing inspiration from the design principles of the London Marathon Map to ensure a unified and coherent narrative flow (Heer et al., 2010).
- 2. *Interest retention*: We incorporated storytelling techniques to engage readers through the depiction of decision-making processes and events, both related and unrelated to diabetes. This narrative approach enables readers to better understand the lived experiences of each patient, enhancing engagement and empathy (Segel & Heer, 2010)
- 3. *Personally relatable content*: To create a memorable and impactful visualization, we integrated personal content such as photos, inner thoughts, and dialogues. These elements foster a stronger emotional connection with the audience, making the visual narrative more relatable and resonant (Vande Moere et al., 2010).
- 4. *Easily recognizable content*: To cater to the runners' segment, we integrated iconic images representing carbohydrate-fueling strategies. These recognizable elements enhance the visual appeal and relevance of the narrative for the target audience (Hullman & Diakopoulos, 2011).

In terms of credibility and trust, we ensured data quality and reliability for the narrative visualization through the following measures:

- 1. *Data source identification*: All information presented in the visual narrative was obtained with informed consent from the patients, ensuring transparency and ethical considerations (Denzin & Lincoln, 2003).
- 2. *Data accuracy and honesty*: The datasets used in this study will be made available to the audience, allowing for validation and confirming the ethical and accurate representation within the visual narrative.

The heuristic framework and design elements utilized in the creation of our visual narrative are summarized in Table 1.

Category	Heuristic	Design Element		
Composition	Logical layout	Situated cartography utilizing marathon map as reference		
	Information density	Segmentation of information for selective exploration		
	Mindful use of color	Color palettes aligned with clinical glycemic targets		
	Textual integration	Optimistic tone and text alignment for motivational impact		
Reader experience	Cohesiveness	Data consistency for enhanced understanding		
	Interest retention	Storytelling to maintain reader engagement		
	Personally relatable content	Inclusion of personal experiences		
	Easily recognizable content	Integration of familiar graphic elements		
Credibility	Data source	Informed consent		
	Data accuracy	Datasets available		

	T	a	bl	e	1
--	---	---	----	---	---

3.2 Sociodemographic subjects' characteristics

Table 2 provides an overview of the socio-demographic and clinical characteristics of the three participants involved in this study. The participants shared common characteristics, with an average age of 44 ± 2 years and 39 ± 5 years of experience managing T1D. Their commitment to physical activity was an average of 21 ± 14 years engaging in regular exercise. Collectively, the three participants had an average of 22 years of education. Furthermore, they demonstrated varied experience in running, ranging from 1 to 5 years, with Case 3 having embarked on his maiden marathon journey. These individuals utilized different insulin administration methods, two of them used

Characteristics	Case 1	Case 2	Case 3
Gender	female	male	male
Age (years)	45	45	41
Educational level (years)	25	17	20
Diabetes duration since diagnosis (years)	42	33	41
CGM system use (years)	5	10	15
Running experience (years)	5	5	1
Prior marathon races	2	5	0
Years participating in physical activity	28	5	30
HbA1c	7	7,2	5,4
ВМІ	19,2	21,2	19,6

Table 2 Reported case: Sociodemographic information,diabetes data and training data.

insulin pumps and one of them multiple injections, with an average of 10 ± 5 years of CGM system use. Importantly, their reported HbA1c values, main marker for diabetes control, of $6.5\% \pm 1$.

3.2.1 Case 1

Is a woman aged 45 years and had been living with T1D for 40 years at the time of competing. She had been using Medtronic Minimed 780G for 2 years and had used Medtronic insulin pumps since 2017. She had a regular training routine, with a weekly training volume of 48.3 km in the 4 months leading up to the marathon. She had previously participated in two major marathons, Chicago in 2019 and New York in 2021, where she encountered issues with her CGM system, losing the signal during the runs. On both occasions, she had to switch her insulin pump to manual mode to receive basal insulin infusion, because the auto mode requires the CGM signal for the artificial pancreas to infuse insulin. She also experienced the same problem during her last long run before the marathon.

In anticipation of signal interference in future marathons, the athlete, in collaboration with her medical team, devised a strategy for the race. She planned to use the insulin pump auto mode until the start of the run and then switch to manual mode with a 30% of her average basal insulin for the duration of the race. Her pre-race breakfast consisted of an unbolused snack with 10 grams of carbohydrates and 5 grams of protein (pita bread and peanut butter). She also planned to consume 8 grams of carbohydrates and hydrate every 5 km from the start of the race.

On 23 April 2023, she participated in the London Marathon. She arrived at the starting point 2,5 hours beforehand as recommended by the marathon organizers with her glycemia in target range. Two hours before the competition, the temporary glycemic target was set to 150 mg/dL. Immediately before competition start, she noticed her glycemia had risen to 214 mg/dL (Figure 2). She decided not to bolus neither take any carbs at that moment, because she thought the running was going to get her levels back in target. On km 4, as her interstitial glucose was 261 mg/dL, she administered a 0.5 IU insulin bolus and another equal bolus 20 minutes after (281 mg/dL). She reported feeling nauseous and thought of the symptoms were because of her ketone level. On km 10 her glucose level reading was 301, so she decided to administer a larger bolus of 1 IU insulin and ingested an 8 g of carbohydrate chew, to build energy reserves and not to risk experiencing a hypoglycemia. From kilometer 15 on, the athlete resumed her original strategy and kept ingesting 8 grams of carbohydrates every 5K. Figure 1 presents the visual narrative for this patient.



Figure 1 Case 1 visual narrative.

3.2.2 Case 2

The participant, a 45-year-old male with 33 years living with T1D, embarked on the London Marathon 2023 with a determination to conquer both the physical demands of the race and the intricate challenges of diabetes management. His running journey had commenced at the age of 40, motivated by a desire to preempt age-related health issues through active engagement in physical activity.

His background encompassed five years of running experience, including participation in five previous marathons, all of which set the stage for his London Marathon endeavor. Setting a goal of completing the race in under five hours, the runner approached the event equipped with a hydration backpack filled with a personalized sports mix, not only for convenience but also to minimize waste.

Training played a pivotal role in his preparation. He structured his regimen with a deliberate focus on optimizing diabetes management. A focal point was the 80/20 rule, wherein 80% of his training occurred within Zone 2, while the remaining 20% involved higher intensity zones. Key components included interval training, easy 5K runs, regular park runs, and long-distance training sessions.

On the day of the London Marathon, meticulous diabetes management strategies were employed. Utilizing a Medtronic 670 insulin pump alongside the Freestyle Libre continuous glucose monitoring system, the participant implemented a pre-race basal insulin adjustment of 5%, ensuring a stable foundation for the race ahead. During the marathon, he adopted a precise carb-fueling approach, consuming ginger electrolyte mix at five-minute intervals and carb gels every 30 minutes.

As the race unfolded, challenges arose in blood glucose management. At approximately mile 13, he noted a rise in blood glucose levels beyond clinically recommended thresholds. Responding swiftly, he elevated the insulin infusion rate to 10%, all while adhering to his established carb fueling routine. Mile 16 marked a turning point, as the runner proactively administered 2 units of insulin, resulting in a favorable trend reversal and subsequent blood glucose reduction.

The culmination of his unwavering commitment and meticulous planning manifested in an impressive finishing time of 4 hours, 46 minutes, and 20 seconds. The participant's triumph extended beyond the realm of mere athletic achievement, encapsulating the culmination of a lifelong journey managing T1D. Through strategic diabetes management, diligent training, and an indomitable spirit, he successfully demonstrated the potential for individuals with diabetes to excel in athletic pursuits while effectively managing their condition. This achievement serves as a testament to the capacity of meticulous preparation and targeted diabetes management strategies to facilitate extraordinary accomplishments in the realm of marathon running. Figure 2 presents the visual narrative for this patient.



Figure 2 Case 2 visual narrative.

3.2.3 Case 3

The individual is a 41-year-old male who has been living with T1D since infancy. He had utilized CGM for the past 18 years and has engaged in sports as a platform for inspiration, particularly cycling. This was his inaugural marathon experience, prompted by witnessing a friend achieve a personal record during the Berlin Marathon in the previous year. The collective energy and determination of the runners crossing the finish line served as a significant source of motivation.

The patient's goal extended beyond merely completing a marathon; he aspired to achieve a time of personal pride. Training for the marathon spanned a relatively brief duration of six weeks. The regimen involved six to seven weekly workouts, including cardiovascular exercises, muscular training, and running. The metabolic challenges of running contrasted with cycling, his primary sport. Throughout this preparation phase, his average glucose levels were exceptionally stable, akin to a non-diabetic profile, which he found gratifying.

Nutritional considerations played a pivotal role in his training routine. Given his role as a middle-aged individual with multiple responsibilities, his appetite was not substantial. Following established practices from non-diabetic individuals, he focused on carbohydrate loading to optimize glycogen stores. In this context, he aimed to facilitate glucose predictability and ensure adequate energy for the marathon. In the days leading up to the race, the individual maintained a controlled dietary intake, particularly emphasizing carbohydrate consumption. However, the night before the marathon, he encountered an unexpected shift in glucose levels. Despite adhering to previous patterns, his glucose levels deviated significantly, reaching elevated levels during the early morning hours of the marathon day. In response to this unanticipated hyperglycemia, he administered additional insulin to mitigate the surge in glucose.

On race day, an hour and 10 minutes before the start his blood glucose was still high (220 mg/dL), so he took 2 more insulin units, incorporating a precise timing for a glucose spike he was used to getting on the first kilometers of his runs. 20 minutes before that start of the race, blood glucose finally was in range (140 mg/dL) and he took his usual pre-race isotonic drink, getting his usual spike on the following minutes. However, unforeseen challenges arose during the race, including a sudden drop in glucose levels and recurring bouts of vomiting from mile 10 to mile 16. These complications disrupted his pacing and overall race experience. Including a strategy to get gels in his cheeks for the glucose to be absorbed and avoid more vomiting.

On mile 13, half of the race when and when he believed the true challenge commences, the runner realized he was not going to be able to meet his expected goal, and once the vomiting stopped, he shifted his strategy and decided just to enjoy the rest of the race. Figure 3 presents the visual narrative for this patient.



Figure 3 Case 3 visual narrative.

4 Discussion

All three athletes effectively managed their glycemic control during the marathon, aligning with recommended strategies for glycemic control during exercise competition (Riddell et al., 2020). Although they didn't achieve their anticipated marathon times, they perceived their race experiences positively and took pride in their accomplishments, demonstrating a resilient perspective consistent with self-efficacy (Bandura, 1977).

While presenting these cases in a positive light might seem biased, it's crucial to emphasize that this optimistic view is based on the athletes' own evaluations and the data they generously shared. This aligns with Frank's concept of illness as an occasion for generosity (Frank, 2004). Their willingness to participate and collaborate underscores the potential value of this research, reflecting the expressed needs of the T1D community and contributing to the re-moralization of illness and its treatment, in line with a broader shift towards a more compassionate and holistic approach to health (Frank, 2004).

Recognizing that individuals with T1D often turn to peer mentoring for practical insights and relatable stories, a visual narrative can encapsulate their preferences and needs more effectively than traditional healthcare provider advice (Dizon et al., 2019). In this context, the autoethnographic approach of this study aligns with the idea that the researcher's own experience can serve as valuable data for creating situated cartography (Clarke, 2005).

Data-related challenges in healthcare share commonalities with other domains, encompassing issues of data integration, manipulation, accessibility, and comprehensibility (Bhartiya & Mehrotra, 2014). However, the healthcare field presents distinct domain-specific complexities that warrant special attention, such as the breath of use, data complexity and statistical rigor (Gotz & Borland, 2016).

The breadth of healthcare applications spans from personalized point-of-care interventions to large-scale population health analyses, necessitating tailored visualization tools for diverse practitioner workflows (Gotz & Borland, 2016). In diabetes management, for instance, patients must comprehend treatment information recommended by endocrinologists, while also being responsible for daily treatment actions. Such dual perspectives underscore the importance of accommodating both patient and care provider needs in data visualizations. The employed visual narrative for a marathon run acknowledges this dual audience, offering diverse ways to interpret glycemic data and contextual events along the marathon track.

Healthcare data is inherently complex, involving vast patient cohorts, numerous variables, cross-referencing from multiple sources, and often missing or incomplete data. Clinicians must synthesize extensive patient records, spanning years and including unstructured clinical notes (Norman, 2013). With the integration of artificial intelligence, genomics, genetics, and wearables, healthcare data complexity continues to grow, particularly in T1D.

Existing platforms statistically summarize patient performance but may lack nuanced patient insights. Visual narratives are essential for effectively presenting this complexity (Hullman & Diakopoulos, 2011).

Statistical rigor is crucial in healthcare due to high-stakes medical (Gotz & Borland, 2016). The visual narrative here presented, incorporates quantitative data with meticulous statistical rigor to reveal clinical risks associated with marathon running decisions. Notably, running at hyperglycemic levels carries potential health risks (Bergford et al., 2023), underscoring the importance of data-driven insights for informed decision-making.

The complexity of combining and monitoring quantitative measurements, data transmission, and phenomenological lived experiences generates laborious practices, also known as "data rituals" (Forlano, 2017). Under endurance physical activity, data rituals can also include nutrition information, insulin sensitivity and kinetics, among others (Colberg et al., 2015). The latter adds further complexity to the challenge of processing all these data in the case of a marathon runner with T1D (Montt-Blanchard et al., 2022). This individual living with T1D and engaging in a marathon race could be considered a "continuous data integrator" (Montt-Blanchard et al., 2022).

Considering the interaction between data rituals and the unique challenges posed by marathon races for individuals with T1D, exercise recommendations require careful consideration (Tagougui et al., 2019). While guidelines exist to mitigate exercise-related hypo- and hyperglycemic risks, their practical implementation must be highly individualized, particularly when monitoring blood ketones and glucose levels during a marathon. Addressing these challenges is crucial, necessitating further research and tailored strategies to ensure the safety, feasibility, and optimal glucose management of marathon runners with T1D.

The array of factors involved in marathon participation highlights the importance of presenting relevant data within the clinical context. Effective data visualization varies across medical conditions, as different specialties demand distinct perspectives. Advancements in visualization techniques and analytics are essential to support patient-centered organization, prioritization, and summarization of medical records.

Building upon David Gotz and David Borland's insights regarding the presence, identity, and role of a human protagonist in disease stories (Gotz & Borland, 2016) our study group aims to assess the proposed visual narratives in collaboration with a cohort of T1D runners and healthcare providers. This collaborative effort seeks to evaluate the acceptance and contribution of the visual narratives to diabetes management strategies specifically tailored for marathon running.

5 Conclusions

Individualized exercise recommendations are necessary for marathon runners with T1D. Implementing guidelines pose challenges that require practical adaptations. Further research is needed to develop tailored exercise recommendations and education material considering patient experience and needs, ensuring safety and optimal glucose management during intense physical activities.

6 Limitations

This study is hypothesis generating and underpowered to draw any reliable conclusions on diabetes management strategies recommendations for marathon running. Prospective randomized studies are required to evaluate this further.

Acknowledgements

The authors would like to express their sincere gratitude to Ian Anderson and Phil Sutherland for their enthusiastic collaboration during the interview and design phases of this research. Their contributions in providing information, data, and constructive feedback, as well as their diligent review of the findings and visual narratives, have been instrumental in achieving the research objectives and enhancing the patient-centered approach within this investigation.

References

Atkinson, P. (2015). For ethnography. SAGE.

- Bandura, A. (1977). Self-efficacy: Toward a unifying theory of behavioral change. *Psychological Review*, 84(2), 191–215. https://doi.org/10.1037/0033-295X. 84.2.191
- Battelino, T., Danne, T., Bergenstal, R. M., Amiel, S. A., Beck, R., Biester, T., Bosi, E., Buckingham, B. A., Cefalu, W. T., Close, K. L., Cobelli, C., Dassau, E., DeVries, J. H., Donaghue, K. C., Dovc, K., Doyle, F. J., Garg, S., Grunberger, G., Heller, S., ... Phillip, M. (2019). Clinical targets for continuous glucose monitoring data interpretation: Recommendations from the international consensus on time in range. *Diabetes Care*, *42*(8), 1593–1603. https://doi. org/10.2337/dci19-0028
- Belk, R. W., Sherry, Jr., J. F., & Wallendorf, M. (1988). A naturalistic inquiry into buyer and seller behavior at a swap meet. *Journal of Consumer Research*, 14(4), 449. https://doi.org/10.1086/209128
- Bergford, S., Riddell, M. C., Jacobs, P. G., Li, Z., Gal, R. L., Clements, M. A., Doyle, F. J., Martin, C. K., Patton, S. R., Castle, J. R., Gillingham, M. B., Beck, R. W., Rickels, M. R., Calhoun, P., & for the TIDEXI Study Group. (2023). The type 1 diabetes and exercise initiative: Predicting hypoglycemia risk during exercise for participants with type 1 diabetes using repeated measures random forest. *Diabetes Technology & Therapeutics*, dia.2023.0140. https://doi.org/10.1089/dia.2023.0140

Besomi, M., Leppe, J., Silvestre, M. C. D., & Setchell, J. (2018). SeRUN® study: Development of running profiles using a mixed methods analysis. *PLOS ONE*, 13(7), e0200389. https://doi.org/10.1371/journal.pone.0200389

- Bhartiya, S., & Mehrotra, D. (2014). Challenges and recommendations to healthcare data exchange in an interoperable environment. *Electronic Journal of Health Informatics*, 8.
- Bohn, B., Herbst, A., Pfeifer, M., Krakow, D., Zimny, S., Kopp, F., Melmer, A.,
 Steinacker, J. M., & Holl, R. W. (2015). Impact of physical activity on glycemic control and prevalence of cardiovascular risk factors in adults with type 1 diabetes: A cross-sectional multicenter study of 18,028 patients. *Diabetes Care*, *38*(8), 1536–1543. https://doi.org/10.2337/dc15-0030

Campbell, J. (2008). The hero with a thousand faces (3rd ed). New World Library.

- Cauza, E., Hanusch-Enserer, U., Strasser, B., Ludvik, B., Kostner, K., Dunky, A., & Haber, P. (2005). Continuous glucose monitoring in diabetic long distance runners. *International Journal of Sports Medicine*, 26(9), 774–780. https://doi. org/10.1055/s-2004-830561
- Clarke, A. E. (2005). *Situational analysis: Grounded theory after the postmodern turn*. Sage Publications.
- Cohen, D., & Crabtree, B. (2006). *Qualitative research guidelines project*. http://www.qualres.org/
- Colberg, S. R., Laan, R., Dassau, E., & Kerr, D. (2015). Physical activity and type 1 diabetes: Time for a rewire? *Journal of Diabetes Science and Technology*, 9(3), 609–618. https://doi.org/10.1177/1932296814566231
- Denshire, S. (2010). The art of 'writing in' the hospital under-life: Auto-ethnographic reflections on subjugated knowledges in everyday practice. *Reflective Practice*, *11*(4), 529–544. https://doi.org/10.1080/14623943.2010.505721
- Denzin, N. K., & Lincoln, Y. S. (Eds.). (2003). *The landscape of qualitative research: Theories and issues* (2nd ed). Sage.
- Ding, C., Chooi, Y. C., Chan, Z., Lo, J., Choo, J., Ding, B. T. K., Leow, M. K.-S., & Magkos, F. (2019). Dose-dependent effects of exercise and diet on insulin sensitivity and secretion. *Medicine & Science in Sports & Exercise*, 51(10), 2109–2116. https://doi.org/10.1249/MSS.000000000002020
- Dizon, S., Malcolm, J., Rowan, M., & Keely, E. J. (2019). Patient perspectives on managing type 1 diabetes during high-performance exercise: What resources do they want? *Diabetes Spectrum*, *32*(1), 36–45. https://doi.org/10.2337/ ds18-0016
- Edmunds, S., Roche, D., Stratton, G., Wallymahmed, K., & Glenn, S. M. (2007). Physical activity and psychological well-being in children with Type 1 diabetes. *Psychology, Health & Medicine*, *12*(3), 353–363. https://doi.org/ 10.1080/13548500600975446
- Errey, N., Liang, J., Leong, T. W., & Zowghi, D. (2023). Evaluating narrative visualization: A survey of practitioners. *International Journal of Data Science* and Analytics. https://doi.org/10.1007/s41060-023-00394-9
- Forlano, L. (2017). Data rituals in intimate infrastructures: Crip time and the disabled cyborg body as an epistemic site of feminist science. *Catalyst: Feminism, Theory, Technoscience*, 3(2), Article 2. https://doi.org/10.28968/ cftt.v3i2.28843

- Foster, N. C., Beck, R. W., Miller, K. M., Clements, M. A., Rickels, M. R., DiMeglio, L. A., Maahs, D. M., Tamborlane, W. V., Bergenstal, R., Smith, E., Olson, B. A., Garg, S. K., & for the T1D Exchange Clinic Network. (2019). State of type 1 diabetes management and outcomes from the T1D exchange in 2016–2018. *Diabetes Technology & Therapeutics*, 21(2), 66–72. https://doi.org/10.1089/ dia.2018.0384
- Frank, A. W. (2004). *The renewal of generosity: Illness, medicine, and how to live.* University of Chicago Press.
- Gotz, D., & Borland, D. (2016). Data-driven healthcare: Challenges and opportunities for interactive visualization. *IEEE Computer Graphics and Applications*, *36*(3), 90–96. https://doi.org/10.1109/MCG.2016.59
- Heer, J., Bostock, M., & Ogievetsky, V. (2010). A tour through the visualization zoo: A survey of powerful visualization techniques, from the obvious to the obscure. *Queue*, 8(5), 20–30. https://doi.org/10.1145/1794514.1805128
- Holman Jones, S. (2005). Autoethnography: Making the personal political.In N. K. Denzin & Y. S. Lincoln (Eds.), *The sAGE handbook of qualitative research* (3rd ed). Sage Publications.
- Hullman, J., & Diakopoulos, N. (2011). Visualization rhetoric: Framing effects in narrative visualization. *IEEE Transactions on Visualization and Computer Graphics*, *17*(12), 2231–2240. https://doi.org/10.1109/TVCG.2011.255
- Kosara, R., & Mackinlay, J. (2013). Storytelling: The next step for visualization. *Computer*, 46(5), 44–50. https://doi.org/10.1109/MC.2013.36
- Ku, B., & Lupton, E. (2020). *Health design thinking: Creating products and services for better health*. Cooper Hewitt.
- Lewiss, R. E., & Lupton, E. (2021). What is health design and why should it be central to your clinical practice in 2021. *European Journal of Emergency Medicine*, 28(3), 169–170. https://doi.org/10.1097/MEJ.00000000000821
- McClure, R. D., Alcántara-Cordero, F. J., Weseen, E., Maldaner, M., Hart, S., Nitz, C., Boulé, N. G., & Yardley, J. E. (2023). Systematic review and meta-analysis of blood glucose response to high-intensity interval exercise in adults with type 1 diabetes. *Canadian Journal of Diabetes*, *47*(2), 171–179. https://doi.org/10.1016/j.jcjd.2022.11.006
- Meuschke, M., Garrison, L. A., Smit, N. N., Bach, B., Mittenentzwei, S., Weiß, V., Bruckner, S., Lawonn, K., & Preim, B. (2022). Narrative medical visualization to communicate disease data. *Computers & Graphics*, *107*, 144–157. https:// doi.org/10.1016/j.cag.2022.07.017
- MiniMed 670G Safe Basal | Medtronic. (2018, December 5). Medtronic Diabetes. https://www.medtronicdiabetes.com/customer-support/minimed-670gsystem-support/safe-basal
- Mittenentzwei, S., Weiß, V., Schreiber, S., Garrison, L. A., Bruckner, S., Pfister, M., Preim, B., & Meuschke, M. (2023). Do disease stories need a hero? Effects of human protagonists on a narrative visualization about cerebral small vessel disease. *Computer Graphics Forum*, 42(3), 123–135. https://doi.org/10.1111/ cgf.14817
- Montt-Blanchard, D., Dubois-Camacho, K., Costa-Cordella, S., & Sánchez, R.
 (2022). Domesticating the condition: Design lessons gained from a marathon on how to cope with barriers imposed by type 1 diabetes. *Frontiers in Psychology*, *13*, 1013877. https://doi.org/10.3389/fpsyg.2022.1013877

- Moy, C. S., Songer, T. J., LaPorte, R. E., Dorman, J. S., Kriska, A. M., Orchard, T. J., Becker, D. J., & Drash, A. L. (1993). Insulin-dependent diabetes mellitus, physical activity, and death. *American Journal of Epidemiology*, *137*(1), 74–81. https://doi.org/10.1093/oxfordjournals.aje.a116604
- Norman, D. A. (2013). *The design of everyday things* (Revised and expanded edition). Basic Books.
- Norman, D. A. (2023). *Design for a better world: Meaningful, sustainable, humanity centered*. The MIT Press.
- Oishi, A., Makita, N., Kishi, S., Isogawa, A., & Iiri, T. (2018). Continuous glucose monitoring of a runner during five marathons. *Science & Sports*, *33*(6), 370– 374. https://doi.org/10.1016/j.scisp0.2018.05.001
- Riddell, M. C., Gallen, I. W., Smart, C. E., Taplin, C. E., Adolfsson, P., Lumb, A.
 N., Kowalski, A., Rabasa-Lhoret, R., McCrimmon, R. J., Hume, C., Annan, F.,
 Fournier, P. A., Graham, C., Bode, B., Galassetti, P., Jones, T. W., Millán, I. S.,
 Heise, T., Peters, A. L., ... Laffel, L. M. (2017). Exercise management in type 1
 diabetes: A consensus statement. *The Lancet Diabetes & Endocrinology*, 5(5),
 377–390. https://doi.org/10.1016/S2213-8587(17)30014-1
- Riddell, M. C., Scott, S. N., Fournier, P. A., Colberg, S. R., Gallen, I. W., Moser, O., Stettler, C., Yardley, J. E., Zaharieva, D. P., Adolfsson, P., & Bracken, R. M. (2020). The competitive athlete with type 1 diabetes. *Diabetologia*, 63(8), 1475–1490. https://doi.org/10.1007/s00125-020-05183-8
- Segel, E., & Heer, J. (2010). Narrative visualization: Telling stories with data. *IEEE Transactions on Visualization and Computer Graphics*, 16(6), 1139–1148. https://doi.org/10.1109/TVCG.2010.179
- Soleimanpour, S. A., & Stoffers, D. A. (2013). The pancreatic β cell and type 1 diabetes: Innocent bystander or active participant? *Trends in Endocrinology & Metabolism*, 24(7), 324–331. https://doi.org/10.1016/j.tem.2013.03.005
- Stadler, M., Peric, S., Strohner-Kaestenbauer, H., Kramar, R., Kaestenbauer, T., Reitner, A., Auinger, M., Kronenberg, F., Irsigler, K., Amiel, S. A., & Prager, R. (2014). Mortality and incidence of renal replacement therapy in people with type 1 diabetes mellitus–A three decade long prospective observational study in the Lainz T1DM cohort. *The Journal of Clinical Endocrinology & Metabolism*, 99(12), 4523–4530. https://doi.org/10.1210/jc.2014-2701
- Sun, G.-D., Wu, Y.-C., Liang, R.-H., & Liu, S.-X. (2013). A survey of visual analytics techniques and applications: State-of-the-art research and future challenges. *Journal of Computer Science and Technology*, 28(5), 852–867. https://doi.org/10.1007/s11390-013-1383-8
- System User Guide. MiniMedTM 780G. (2022). Medtronic.
- Tagougui, S., Taleb, N., Molvau, J., Nguyen, É., Raffray, M., & Rabasa-Lhoret, R. (2019). Artificial pancreas systems and physical activity in patients with type 1 diabetes: Challenges, adopted approaches, and future perspectives. *Journal of Diabetes Science and Technology*, *13*(6), 1077–1090. https://doi. org/10.1177/1932296819869310
- Weiss, K., Thuany, M., Scheer, V., Ouerghi, N., Andrade, M. S., Nikolaidis, P. T., Cuk, I., & Knechtle, B. (2023). How to end up on the podium after running a 6-days-run with type 1 diabetes mellitus—A case study and literature review. *European Review for Medical and Pharmacological Sciences*, 27(1), Article 1. https://doi.org/10.26355/eurrev_202301_30856

- Xue, H., & Desmet, P. M. A. (2019). Researcher introspection for experiencedriven design research. *Design Studies*, *63*, 37–64. https://doi.org/10.1016/j. destud.2019.03.001
- Yardley, J. E., Sigal, R. J., Kenny, G. P., Riddell, M. C., Lovblom, L. E., & Perkins, B. A. (2013). Point accuracy of interstitial continuous glucose monitoring during exercise in type 1 diabetes. *Diabetes Technology & Therapeutics*, 15(1), 46–49. https://doi.org/10.1089/dia.2012.0182
- Zarkogianni, K., Mitsis, K., Litsa, E., Arredondo, M.-T., Fico, G., Fioravanti, A., & Nikita, K. S. (2015). Comparative assessment of glucose prediction models for patients with type 1 diabetes mellitus applying sensors for glucose and physical activity monitoring. *Medical & Biological Engineering & Computing*, 53(12), 1333–1343. https://doi.org/10.1007/s11517-015-1320-9

About the authors

Denise Montt-Blanchard

denisemontt@uc.cl Pontificia Universidad Católica de Chile Chile

María Teresa Onetto

mtonettof@gmail.com Pontificia Universidad Católica de Chile Chile

Raimundo Sánchez

raimundosanchezu@gmail.com The University of Queensland, Australia Adolfo Ibáñez University, Chile

Submission date/Artigo recebido em: 1/8/2023 Approvement date/Artigo aprovado em: 15/8/2023