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SPECIAL ARTICLE

Towards a personalised digital care in type 1 diabetes. Are we ready?



Hacia una atención digital personalizada para las personas con diabetes tipo 1. ¿Estamos preparados?

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Type 1 diabetes mellitus (T1DM) is a chronic disease characterized by autoimmune destruction of pancreatic beta cells. It has posed a constant challenge to public health systems over the past 50 years. The incidence of T1DM is increasing at a rate of 3% up to 5% annually in European countries, especially among children under 5 years of age. This trend involves a future scenario with a larger population of young adults living with T1DM, facing longer disease durations and an increased risk of chronic complications. Additionally, it is estimated that early diagnosis of T1DM is associated with a reduction in life expectancy by 10–12 years. ¹

Currently, we are witnessing a significant transformation in care processes driven by technological innovation, digitalization, and increased knowledge of T1DM among affected individuals. There is also a growing demand to focus care on the patient, incorporating greater integration of multidisciplinary services.

For many years, the management of for individuals with T1DM has been predominantly based on reactive and inperson care models initially involving a higher need for hospitalization (admissions during disease onset, treatment adjustments, or to "optimize glycemic control"), and later shifted to outpatient care, especially for adult patients. Clinical practice guidelines currently recommend periodic, scheduled annual visits. However, this rigid model lacks the flexibility to adapt to individual patient needs or the level of disease control. Moreover, it is challenging—or nearly impossible—to sustain in a saturated public health system that cannot provide the recommended level of care for a growing number of patients.

The COVID-19 pandemic revealed the limitations of this care model for T1DM patients at our center, introducing new challenges. The pandemic occurred at a time of increasing care demand, advancing access to cutting-edge technology for managing the disease, and a more empowered patient population. The use of "remote consultations" emerged and accelerated during the pandemic, mitigating the accessibility barriers to the healthcare system during and after the various "waves." This highlighted 2 clear aspects: on the one hand, the inability of the health care system to expand sufficiently to accommodate all necessary actions for optimal health outcomes in individuals with T1DM. On the other hand, the limited availability of working-age T1DM patients to adhere to the tight schedule of recom-

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mended visits outlined in clinical practice guidelines. This empowered population was already analyzing data from advanced diabetes technologies (such as continuous glucose monitoring [CGM] systems and hybrid closed-loop insulin infusion systems [HCL]) and making decisions for T1DM self-management. These circumstances created an opportunity to rethink the health care process. A shift was needed towards a proactive, individualized model tailored to specific needs at different times, directing resources to those who need them most and avoiding redundant, low-value visits. Our challenge was summarized by one key question: Could we adapt our care model to provide the best attention to our patients while considering the ongoing technological revolution?

Based on this analysis, our center launched the "T1DM Health Care Model Transformation Project." A multidisciplinary working group was formed, including professionals from Endocrinology and Nutrition Services, the Diabetes Unit, the Information Systems Directorate, the Strategy Directorate, the Patient Experience Program, the Quality Directorate, and an external company specializing in technological integration and development.

Project stages and objectives:

- a) Digitally transform the current model to integrate data from all technological devices used for T1DM management into our information system.
- b) Convert electronic health records into structured data formats to create a dashboard based on health outcome indicators, developed following the standards of the International Consortium for Health Outcomes Measurement (ICHOM).
- c) Implement quality improvements for various types of consultations (in-person, remote, phone, video calls, individual and group visits, e-learning programs).
- d) Integrate a dedicated "My Diabetes" section into the "El Meu Clínic" online application (a digital platform for patients at Hospital Clínic de Barcelona), offering specific functionalities to support the care model transformation.
- e) Develop a "T1DM Management Prioritization Program" to categorize patients into 5 groups, personalizing care according to their needs.
- f) Analyze patient experience to evaluate their opinions on current and future care models.

The first major challenge was integrating data from various CGM and HCL devices. With no prior precedents, a legal framework was established to ensure integration. Currently, data is automatically aggregated and exported to our server every 24 h. In the coming future, real-time integration will support managing these devices for hospitalized patients.

In addition to integrating data from devices used in managing T1DM, the project required robust information that would enable us to obtain health outcome indicators in a purpose-designed dashboard. Based on the principles of Michael Porter, a renowned economist and professor at Harvard Business School (MA, USA), we considered it essential to measure health outcomes to improve the efficiency and effectiveness of our system. With the aim of achieving success in patient care and following these principles, various forms were designed to create a structured electronic clinical course based on ICHOM⁵ standards. These standards are

sets of health outcome measures developed to assess the effectiveness of patient care from the patient's perspective. They were specifically designed to measure and compare health outcomes globally. The main characteristics of the indicator set proposed by ICHOM are as follows: a) They focus on outcomes from the patient's perspective; b) They allow for comparisons of results across centers and countries, facilitating the identification of best practices and improving medical care; c) They include multidimensional indicators; d) The standards are developed through a collaborative process involving clinicians, patients, researchers, and other stakeholders, ensuring relevance and practicality; e) They promote transparency and standardization in outcome measurement, crucial for advancing the efficiency and effectiveness of health systems. The structured electronic clinical course was designed in collaboration with the Quality Directorate of our center. The indicators proposed by ICHOM were included along with other relevant metrics identified by the clinical team. Since its launch in early 2024, periodic improvements are being made as new functionalities or more practical ways of presenting information to the care team during medical visits are identified. The development includes the prescription of online questionnaires for patients (quality of life, treatment adherence, etc.), improved visualization of key data from health records, and the integration of information from the clinical prioritization program. Additionally, enhanced visits and educational programs open new avenues for optimizing glycemic control and ensuring greater accessibility and communication with care team professionals.

Regarding the digital platform *El Meu Clínic*, it not only enables viewing of upcoming visits and prescriptions, but also allows individuals with T1DM to manage changes or new visit requests, report severe hypoglycemia episodes, respond to prescribed questionnaires, access data from integrated devices, and receive periodic reports from the prioritization program (analysis of their indicators and the percentage of days in each category since the last visit). In the future, it will also provide access to online training platforms where patients can find information and courses to update their knowledge on diabetes.⁶

The Care Prioritization Program for individuals with T1DM is the cornerstone of the Diabetes Project at our hospital. It is a project designed in-house and fully integrated into our IT system. Patients are enrolled in the program once they are specifically flagged in the electronic health record and their devices are identified. The program can detect errors in the use and integration of device data, offering proposals and tools to solve them. Once enrolled in the program, patients with T1DM are categorized into 5 arbitrary categories based on the following parameters: a) Data obtained from glycemic control, device usage, and performance; b) Recent hospital admission; c) Severe hypoglycemia episode within the last 14 days reported on the digital platform; d) Upcoming pre-scheduled appointments. With all this data, each case is categorized into 1 of these categories: 1) optimal control; 2) suboptimal control; 3) poor control; 4) alert; 5) lack of data. The initial implementation of the project involves a member of the medical team and an advanced role administrative assistant reviewing the patients in each category 2-3 times a week, assessing and deciding actions to take in each case (e.g., scheduling in-person/virtual

appointments, determining prioritization—emergency, preferred, timing, etc.—, with which professional, and into which program). After the pilot phase and results evaluation, the advanced role administrative assistant ("clinical assistant") will manage the program under the supervision of a clinical team member. In cases of good control and no incidents, it is expected that a patient will have 1 in-person visit each year and receive quarterly reports through the digital platform assessing their results. Patients in programs aimed at optimizing T1DM control, those with a recent acute complication, significant hospital admission, or an intercurrent event impacting their T1DM control, will receive individualized care when needed. Emergency care in various modalities (emergency services, day hospital, and 24/7 continuous care phone line) remains unchanged.

Finally, within our center Patient Experience group, 3 focus groups were held (with 20 T1DM patients participating) across different age groups to assess opinions on the current care model and future proposals. Overall, the focus on improving accessibility to the team in case of intercurrent events was rated very positively, and those under 55 favored a mixed in-person/remote follow-up system, emphasizing allocating more resources when follow-up deteriorates and fewer when everything works well. Currently, the analysis of a survey involving more than 500 patients with HCL systems is pending, with the goal of extending the project to most chronic follow-up T1DM patients in our Diabetes Unit.

In conclusion, both the technology applied to T1DM and the data it provides have revolutionized the treatment of T1DM and should also contribute to the transformation of its management process, increasingly focused on the patient, where their empowerment continues to play a fundamental role. This health care process seeks interventions that

add value, avoiding redundant or superfluous ones that contribute to the collapse of public health systems. For these changes to materialize, patients, health care professionals, health organizations, industry, and policymakers must agree to design, organize, and realize the new care project. Only time will tell if we are on the right path and if our proposed change in the T1DM care model positively impacts what truly matters: these individuals' health, well-being, and quality of life. Furthermore, it will reveal if the model is transferable to other care processes and whether this moment marks the beginning of a broader change in patient care.

References

- Svensson J, Ibfelt EH, Carstensen B, Neu A, Cinek O, Skrivarhaug T, et al. Age-period-cohort modelling of type 1 diabetes incidence rates among children included in the EURODIAB25-year follow-up study. Acta Diabetol. 2023;60:73–82, http://dx.doi.org/10.1007/s00592-022-01977-x.
- 2. American Diabetes Association. Standards of medical care in diabetes—2021. Diabetes Care. 2021;44 Suppl 1:S1-232.
- Pueyo I, Viñals C, Mesa A, Giménez M, Conget I. Strategyand results of the massive implementation of reimbursed continuous glucose monitoring in people with type 1 diabetes. Endocrinol Diabetes Nutr (Engl Ed). 2023;70 Suppl 3:73-5, http://dx.doi.org/10.1016/j.endien.2022.03.011.
- Porter ME. What is value in health care? N Engl J Med. 2010;363:2477-81, http://dx.doi.org/10.1056/NEJMp1011024.
- International Consortium for Health Outcomes Measurement. ICHOM Standard Set for Diabetes; 2018. Available from: https://www.ichom.org/standard-sets/set/diabetes/
- El Meu Clínic [Mobile application software]. Hospital Clínic de Barcelona. Available from: https://www.clinicbarcelona. org/elmeuclinic.