

Self-management of insulin therapy among people with diabetes

Autogestão da prática de insulinoterapia em pessoas com diabetes

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 Lourena Ferreira dos Reis Campos¹
 José Cláudio Garcia Lira Neto¹
 Maria Augusta Rocha Bezerra¹
 Ítalo Arão Pereira Ribeiro²
 Ruth Cardoso Rocha¹
 Jéssica de Menezes Nogueira¹
 Mychelangela de Assis Brito¹

¹Universidade Federal do Piauí.
Florianópolis, PI, Brazil.

²Universidade Federal de Mato Grosso do Sul.
Coxim, MS, Brazil.

Corresponding author:

José Cláudio Garcia Lira Neto
BR 343, KM 2,5 – Meladão. CEP: 64800-000.
Florianópolis, PI, Brazil. E-mail: jclira@ufpi.edu.br

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EDITOR IN CHIEF: Ana Fatima Carvalho Fernandes 

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ABSTRACT

Objective: to understand insulin therapy self-management among people with diabetes receiving Primary Health Care. **Methods:** we conducted a qualitative study with 60 people with diabetes using insulin. Data were collected through semi-structured interviews and field notes and analyzed using interpretive description, with IRaMuTeQ supporting lexical exploration. The analysis yielded three analytical categories. **Results:** participants' accounts portrayed insulin therapy self-management as a complex, dynamic process shaped by emotional, social, and structural dimensions. Insulin initiation was marked by fear, resistance, distress, and perceived disease progression but was gradually reframed as a means of managing the condition and gaining autonomy. Everyday practices involved negotiations among treatment recommendations, eating practices, blood glucose monitoring, physical activity, and therapeutic adjustments. Participants also reported gaps in guidance, lack of confidence in administering insulin, and dependence on family members and health care professionals. **Conclusion:** insulin therapy selfmanagement requires more than technical proficiency and depends on ongoing person-centered educational, emotional, and social support responsive to everyday circumstances. **Contributions to practice:** the findings underscore the need to strengthen nurses' role in health education, longitudinal follow-up, and support for autonomy among people with diabetes receiving Primary Health Care. **Descriptors:** Diabetes Mellitus; Insulin; Self-Management; Primary Health Care; Qualitative Research.

RESUMO

Objetivo: compreender como ocorre a autogestão da prática de insulinoterapia em pessoas com diabetes acompanhadas na Atenção Primária à Saúde. **Métodos:** estudo qualitativo, conduzido com 60 pessoas com diabetes em uso de insulina, por meio de entrevistas semiestruturadas, diário de campo e análise interpretativa descritiva, com apoio do *software* IRaMuTeQ. A análise possibilitou a organização dos achados em três categorias temáticas. **Resultados:** a autogestão da insulinoterapia mostrou-se como processo complexo, dinâmico e atravessado por dimensões emocionais, sociais e estruturais. O início do uso da insulina foi marcado por medo, resistência, sofrimento e associação com agravamento da doença, sendo progressivamente ressignificado como possibilidade de controle e autonomia. As práticas cotidianas envolveram negociações entre prescrições, alimentação, monitoramento glicêmico, atividade física e ajustes terapêuticos. Também foram identificadas lacunas nas orientações recebidas, insegurança na aplicação e dependência de familiares e profissionais de saúde. **Conclusão:** a autogestão da insulinoterapia exige mais que domínio técnico, requerendo suporte educativo, emocional e social contínuo, centrado na pessoa e em sua realidade cotidiana. **Contribuições para a prática:** os achados reforçam a necessidade de fortalecer a atuação da enfermagem na educação em saúde, no acompanhamento longitudinal e no apoio à autonomia de pessoas com diabetes na Atenção Primária.

Descritores: Diabetes Mellitus; Insulina; Autogestão; Atenção Primária à Saúde; Pesquisa Qualitativa.

Introduction

Diabetes mellitus (DM) is a chronic noncommunicable disease and a major public health problem⁽¹⁾ because it contributes substantially to morbidity and mortality worldwide, affecting people across demographic groups regardless of geographic location, age, or sex⁽²⁾. Despite therapeutic advances and broader access to treatment, glycemic control remains inadequate in a substantial proportion of people with diabetes⁽³⁾, contributing to complications and poorer quality of life⁽⁴⁾.

Recent estimates indicate that approximately 589 million adults aged 20–79 years live with diabetes, accounting for 11.1% of the global adult population. This number is projected to reach 853 million by 2050, with continued growth, particularly in middle-income countries and urban settings. In addition to its epidemiologic burden, diabetes imposes substantial costs on health systems⁽⁵⁾. In the United States, total costs were estimated at US\$412.9 billion in 2022, while recent analyses indicate that complications such as diabetic peripheral neuropathy may account for nearly US\$45.9 billion in annual costs, driven primarily by hospitalizations, pressure injuries, and amputations^(6–7).

In this context, insulin therapy has been shown to improve glycemic control and may help preserve beta-cell function and prevent diabetes-related complications⁽⁸⁾, particularly when other therapeutic strategies are insufficient to achieve appropriate metabolic targets⁽⁹⁾. Despite these benefits, insulin therapy extends beyond the biomedical dimension of prescribing and constitutes a complex practice that requires people with diabetes to draw on a range of competencies⁽¹⁰⁾.

Insulin administration requires not only technical skills, such as preparing, storing, and injecting insulin, but also cognitive skills related to self-monitoring and interpreting blood glucose levels, adjusting insulin doses based on these measurements, and accounting for dietary patterns and physical activity levels⁽¹¹⁾. Emotional, behavioral, and social factors also

shape insulin therapy management, making it inherently dynamic⁽¹²⁾.

Within this framework, self-management is central to understanding diabetes care. Unlike the traditional concept of adherence, often understood merely as following treatment recommendations, self-management is an active, continuous, and context-dependent process that requires multilevel interventions to address systemic and individual barriers and to account for the complex interplay of cultural, social, and structural factors in diabetes management⁽¹³⁾. This perspective recognizes people's agency in their own care and the role of health services in enabling them to manage their condition proactively⁽¹⁴⁾.

Primary Health Care (PHC) plays a strategic role in this context by providing longitudinal follow-up, education, and self-management support. However, evidence suggests that care provided in PHC does not necessarily translate into self-efficacy or effective self-management in practice, highlighting the need for specific training in health condition management, support from experienced mentors, appropriate guidelines, and comprehensive, integrated chronic care systems^(15–16). This gap underscores the need for a deeper understanding of how people actually manage insulin therapy in their everyday lives.

Despite the relevance of this topic, the literature has largely favored quantitative approaches focused on indicators of glycemic control, treatment adherence, and knowledge of diabetes. There is therefore an important gap in understanding the experiences, practices, and meanings that people with diabetes assign to insulin therapy in everyday life, particularly in PHC. Qualitative studies exploring insulin therapy selfmanagement remain limited, particularly those that account for the complex interplay of individual, social, and organizational factors. Accordingly, the findings may inform improvements in care practices and the development of interventions grounded in qualitative insights and a comprehensive understanding of the complexities of diabetes management, ultimately helping address therapeutic inertia and improve the quality of care for people living with diabetes⁽¹²⁾.

Accordingly, this study aimed to understand insulin therapy self-management among people with diabetes receiving Primary Health Care.

Methods

Study design

We conducted a qualitative study using semi-structured interviews. The study was reported in accordance with the Consolidated Criteria for Reporting Qualitative Research (COREQ).

Setting and data collection period

The study was conducted from October 2024 to January 2025 at urban Basic Health Units (BHUs) in the PHC network of a municipality outside Teresina, the capital of Piauí State, in Northeast Brazil. The municipality has 24 BHUs, 17 in urban areas and 7 in rural areas. We included only urban units because logistical constraints limited access to rural areas (reference withheld for peer review).

In this municipality, care for people with chronic conditions, particularly diabetes, is delivered primarily through PHC, which serves as the entry point to the health system and is responsible for longitudinal follow-up. Family health teams provide ongoing monitoring, home visits, and health education to support glycemic control and prevent complications. This care model is consistent with the guidelines of the Brazilian Unified Health System (SUS), which prioritize comprehensive care, ongoing patient-team relationships, and continuous management of chronic conditions. These elements are essential to reducing morbidity and mortality and improving the population's quality of life (reference withheld for peer review).

Participants and sampling

The study included people with diabetes receiving insulin therapy who were registered with and followed at the municipality's BHUs. Of the 3,578 peo-

ple with diabetes in the municipality, 13.6% use insulin. We used nonprobability convenience sampling to recruit individuals who were available and accessible within the health care setting. Eligible participants were adults aged 18 years or older with a confirmed medical diagnosis of type 1 or type 2 diabetes who had used insulin for at least 6 months and were registered with an urban BHU. We excluded insulin pump users, pregnant women, and individuals who used insulin only as an adjunct in unstructured regimens. The sample size was not intended to achieve statistical representativeness but to capture depth and diversity in participants' accounts of insulin therapy self-management. Data collection ended when informational sufficiency was reached, as successive interviews reiterated previously identified meaning units and yielded no new analytically relevant elements.

Data collection and interview guide

This study is part of a larger research project entitled "Analysis of insulin therapy practices among people with diabetes receiving Primary Health Care." After institutional authorization was obtained, the research team underwent training in the ethical conduct of research involving human participants; diabetes and insulin therapy; the steps involved before and during insulin preparation and administration; welcoming and supporting participants; skin assessment at injection sites; and data collection procedures, including interviews, direct observation using a checklist, and audiovisual recording. One month before data collection began, we pilot-tested and refined the data collection instruments.

Nurses and community health workers (CHWs) helped recruit participants by inviting them within their assigned communities and at the BHUs. Interviews were scheduled based on participants' availability and conducted by the principal researcher, an undergraduate nursing student who had received specific training to ensure a consistent and ethical interview process. Data were collected in a private room at the BHUs after participants had read and signed the

informed consent form. The semi-structured interviews explored experiences, perceptions, and practices related to insulin therapy self-management and were supplemented by the collection of sociodemographic data. Interviews were audio-recorded, transcribed in full, and supplemented with field notes.

The researchers developed the interview guide, which three nurse experts reviewed for content coherence, clarity, relevance, alignment with the study objective and theoretical framework, comprehensibility, and applicability to similar contexts. The review also assessed the guide's suitability for the target population and study setting. The interview prompts were as follows: "What difficulties do you face in managing your insulin therapy?" "How have you adapted to diabetes treatment?" "What guidance have you received on diabetes management, and how would you evaluate that guidance?" "What do you understand about diabetes and its management?" "What factors do you believe influence your glycemic control?" "What changes have occurred in your life since you were diagnosed with diabetes?" "What do you know about lipodystrophy associated with insulin use?" "Do you rotate your insulin injection sites?" "How were you instructed to do so, and how do you perform this practice?"

Data analysis

We analyzed the data using interpretive description, an approach grounded in nursing's disciplinary epistemology and designed to generate clinically applicable understandings of participants' experiences, perceptions, and the meanings they assigned to the phenomenon under study. We combined interpretive description with the chronic illness self-management framework⁽¹⁷⁾. Within this framework, selfmanagement encompasses three interdependent dimensions: medical management, involving medication use, monitoring, recognition of signs, and therapeutic decision-making; role management, involving adaptations in everyday, family, social, and work life; and emotional management, involving coping with fear, uncertainty, and distress, as well as accepting the chronic con-

dition and reconstructing one's identity. We therefore interpreted insulin therapy not merely as a prescribed technique but as a lived practice that people with diabetes negotiate and reframe in everyday life.

The analytical process comprised six stages: (1) transcription and data organization; (2) in-depth reading of the material; (3) identification of meaning units; (4) coding; (5) critical interpretive analysis; and (6) construction of the findings⁽¹⁸⁾. We identified meaning units through both inductive reading of the narratives and framework-informed analysis based on the dimensions of chronic illness self-management. The analysis examined how participants managed insulin therapy, reorganized their routines, and assigned emotional and social meanings to treatment.

We refined the interview transcripts in three stages. First, we transcribed the interviews verbatim, preserving participants' original wording. Next, we reviewed the transcripts for spelling and cohesion without changing their meaning. Finally, we prepared the textual corpus in accordance with the software requirements.

To support the analysis, we used the Interface de R pour les Analyses Multidimensionnelles de Textes et de Questionnaires (IRaMuTeQ) to perform lexical and statistical analyses of the textual corpus, including descending hierarchical classification, similarity analysis, and word cloud generation. These analyses contributed to identifying discourse patterns and organizing the data. Software-generated outputs were used as complementary resources for lexical exploration and did not replace the qualitative interpretation of the narratives. They supported the visualization of word frequencies, co-occurrences, and semantic relationships, while we grounded the analytical categories in an in-depth reading of the interviews and the chronic illness self-management framework.

We identified meaning units through an in-depth reading of the transcripts and examination of the software-generated outputs, then grouped them into thematic codes. The analysis yielded three analytical categories: Impact of diagnosis and identity (re) construction at insulin initiation; Situated selfman-

agement: everyday negotiations between treatment recommendations and real life; and Support networks and gaps in care for insulin therapy self-management.

We used reflexivity, triangulation, and analytical validation to strengthen the study's rigor. Reflexivity was supported by field notes documenting the researcher's perceptions, contextual impressions, interactions with participants, and potential influence on data production and interpretation. Triangulation integrated multiple data sources and analytical procedures, including semi-structured interviews, field notes, interpretive reading of the narratives, and IRaMuTeQ-supported lexical analysis. For analytical validation, the researchers reviewed the analytical categories and thematic codes to assess coherence among participants' accounts, meaning units, categories, and the chronic illness selfmanagement framework.

We also conducted a critical interpretive analysis of the narratives, considering the social, cultural, and institutional contexts surrounding participants' experiences, as well as the power relations embedded in health care. Our interpretation of the findings drew on interpretive description, the chronic illness self-management framework, and the scientific literature on diabetes, insulin therapy, PHC, and person-centered care. This integration enabled us to understand insulin therapy self-management as a multidimensional phenomenon involving technical proficiency, decision-making, emotional support, reorganization of everyday life, and ongoing interactions with family members and health care professionals.

Ethical considerations

To ensure privacy and confidentiality, participants were assigned alphanumeric codes consisting of the letter P followed by the number corresponding to their interview order (e.g., P1, P2, P3, P4). The Research Ethics Committee of the Federal University of Piauí approved the study under Certificate of Presentation for Ethical Review no. 78541624.2.0000.5660 and approval no. 6.746.565/2024.

Results

The study included 60 participants with diabetes receiving insulin therapy. Women accounted for 56.7% of the sample (n=34), 58.3% were single or widowed (n=35), and 71.7% self-identified as Black (n=43). Twenty-two participants (36.7%) had up to 9 years of schooling. The mean monthly income was BRL 3,883.00.

Participants understood insulin therapy self-management in PHC as an ongoing process that involves proper insulin administration, blood glucose monitoring, and the adoption of healthy lifestyle habits. They emphasized the need for knowledge of insulin doses, timing, injection technique, and injection-site rotation, as well as the importance of self-care through healthy eating and physical activity. They also perceived self-management as dependent on support from health care teams, particularly the guidance they received and regular follow-up at the BHUs. However, participants reported difficulty understanding the guidance, uncertainty about insulin administration, and challenges in maintaining glycemic control. Their accounts indicated that self-management was shaped by both individual factors and the support provided by health services.

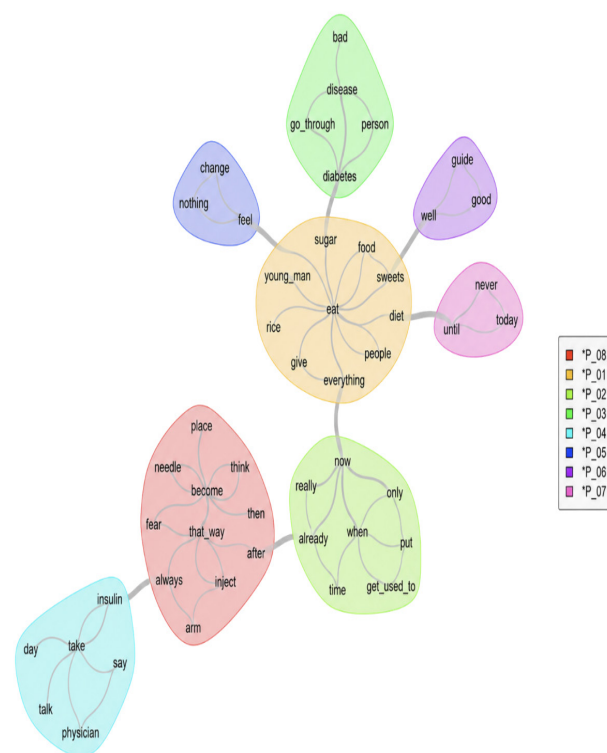
Impact of diagnosis and identity (re)construction at insulin initiation

Participants' initial experiences with insulin therapy had a profound emotional impact, reflected in fear, distress, and perceptions that the condition was severe. Insulin was often associated with disease progression and the possibility of death, reflecting negative social beliefs about diabetes: *It was very hard. I cried a lot. I thought I was going to die and did not have much time left* (P29). *You'll go blind, lose a leg... it's a terrible disease* (P50).

The start of treatment was also marked by resistance and denial, particularly in response to the need for self-injection: *I don't like giving myself injections. I just can't stand it* (P11). *It was a disease I knew nothing about... having to*

“Insulin,” one of the central terms, represented more than a medication in participants’ accounts. It was a key means of managing diabetes and required constant negotiation with the pleasures and needs of everyday life. Emotional and social dimensions were also central. Fear, difficulty, and the need for help suggest that self-management was often accompanied by emotional burden and lack of confidence. Achieving autonomy, therefore, appeared to require care that extended beyond dose prescribing—what to do—to include guidance on administering insulin and support for sustaining self-management over time.

The similarity tree (Figure 2) presents general clusters of words extracted from participants’ accounts. Each cluster comprises semantically related terms and complements the word cloud by highlighting central themes in participants’ perceptions.



*P: Patient

Figure 2 – Similarity tree of representations of insulin use among people with diabetes. Floriano, PI, Brazil, 2025

The similarity tree helped visualize associations among terms related to insulin use, eating practices, injection, fear, and guidance, reinforcing the complexity of everyday management described by participants. The proximity of terms related to guidance and health care professionals suggests that professional support was prominent in participants’ accounts, particularly regarding learning and treatment management.

Adaptation to insulin self-injection also appeared to be gradual. Eating practices were central to diabetes management and required discipline and changes in eating habits, particularly regarding sugar and carbohydrate intake. Overall, participants perceived diabetes as a difficult condition with emotional and behavioral implications. However, regular follow-up, supportive care, and appropriate guidance could make managing the condition less burdensome.

Discussion

The findings indicate that insulin therapy self-management in PHC extends beyond the technical and operational aspects of insulin use; it is a complex, dynamic process profoundly shaped by psychosocial factors that may reduce motivation and hinder participation in structured self-management programs⁽¹⁹⁾. The predominance of participants with lower educational attainment and from socially vulnerable groups suggests that the capacity for self-management cannot be understood apart from the social inequalities that shape people’s access to information, their understanding of guidance, and their autonomy in managing their own care⁽²⁰⁾. In this context, self-management extends beyond treatment adherence and entails an ongoing process of balancing health, identity, and autonomy⁽²¹⁾.

Against this background, although related, self-management and self-care are distinct components of diabetes care. Self-management involves behaviors guided by health care professionals, whereas selfcare refers to actions that individuals undertake independently to maintain their health and prevent complica-

tions. Although often used interchangeably, the two concepts are complementary and support ongoing collaboration between people with diabetes and health care professionals⁽²²⁾.

Participants' initial experiences with insulin therapy—marked by fear, denial, and the perception that insulin signaled disease progression—reflect beliefs influenced by the sociocultural context and dynamically reshaped through experience⁽²³⁾. These perceptions may contribute to initial resistance to treatment and highlight the need to understand the complex, continually evolving affective and cognitive dynamics involved in what may appear to be a straightforward yet disconcerting transition: from being prescribed insulin to incorporating insulin therapy into everyday life⁽²⁴⁾.

The gradual reframing of insulin—from something associated with death to a means of managing the condition and gaining autonomy—was evident in participants' accounts. Although they reported that they now lived well with and accepted diabetes, several recalled anger and difficulty accepting the condition at diagnosis⁽²⁵⁾. This transition reflects a process of identity reconstruction through which people gradually incorporate the chronic condition into their lives, reinforcing the need for person-centered care that recognizes and addresses the emotional dimensions of illness. Insulin therapy may therefore entail a process of biographical reorganization as individuals adjust their practices, expectations, and social relationships to the demands of the chronic condition⁽²⁶⁾.

The analysis of everyday practices shows that ongoing negotiations between biomedical recommendations and the realities of everyday life shape self-management. Eating practices, identified as central to glycemic control, extend beyond their nutritional dimension to encompass cultural, social, economic, and emotional aspects, making dietary change a structural and political process⁽²⁰⁾. Moreover, the coexistence of dietary restrictions and occasional departures from them shows that adherence cannot be reduced to a simple adherence/nonadherence di-

chotomy; rather, it should be understood as a process involving ongoing judgments and considerations by people with diabetes⁽²⁴⁾. Similarly, managing insulin therapy requires ongoing adjustments and frequent monitoring, underscoring the complexity of care and the need for competencies that extend beyond technical procedures to include decision-making, interpretation of signs, and self-regulation.

The findings also reveal an important tension between dependence and autonomy in selfmanagement. Although family and professional support is essential, particularly early in treatment, the lack of structured guidance limits the development of effective self-management because people with diabetes may have difficulty understanding complex health information and making informed decisions about their care⁽²²⁾.

These educational shortcomings suggest that PHC care may still rely on sporadic, poorly structured guidance that is not always tailored to people's individual circumstances, prior knowledge, and specific needs⁽²⁷⁾. The complementary lexical analysis was consistent with patterns identified in the interviews, particularly the prominence of operational terms related to insulin, injection, and eating practices, as well as expressions associated with fear and difficulty. These findings suggest that insulin therapy involves both practical and emotional demands, underscoring the need to integrate technical, educational, and emotional support into the longitudinal care of people with diabetes. Furthermore, the prominence of physicians as the main source of guidance suggests that the multidisciplinary team—particularly nurses—remains underused. Nurses play a strategic role in health education, longitudinal follow-up, and strengthening autonomy.

From a critical perspective, the findings suggest that the prevailing care model continues to prioritize a prescriptive approach centered on “what to do” rather than “how to do it” and “why it should be done,” both of which are essential to informed and sustainable self-management. Fostering autonomy,

therefore, cannot be reduced to shifting responsibility to patients. Rather, it requires shared goal setting and collaboration with health care professionals, as well as strategies to address the psychological challenges of sustaining self-management over time, including structured education and patient empowerment⁽²²⁾.

Finally, this study advances understanding of insulin therapy self-management as a multidimensional phenomenon that requires the integration of technical knowledge, emotional support, supportive social conditions, and longitudinal follow-up. The findings underscore the need to reorient PHC practices by strengthening the role of nursing, expanding health education strategies, and incorporating person-centered approaches that support glycemic control while also promoting autonomy, quality of life, and empowerment in managing one's chronic condition.

Study limitations

Conducting the study in a single municipality may limit the transferability of the findings to other PHC settings with different sociocultural and organizational characteristics. In addition, the sample comprised participants using insulin, most of whom were from socially vulnerable groups. The findings may therefore reflect experiences specific to this population and may not capture the full range of experiences among people with diabetes. Interview-based data may also be subject to recall and social desirability bias, as participants may have emphasized experiences that were more memorable or perceived as more socially acceptable. Although lexical analysis provided additional insight into the meanings participants attributed to insulin therapy, it may not have fully captured the complexity of individual experiences. Finally, the study did not assess objective clinical variables, such as blood glucose levels, or quantitatively measure treatment adherence, thereby limiting direct examination of the relationship between participants' perceptions and clinical outcomes.

Contributions to practice

Incorporating insulin therapy self-management into health professions education and continuing professional development can better prepare health care professionals to care for people with chronic conditions, particularly by strengthening their ability to provide health education, build therapeutic relationships, and address the subjective dimensions of illness. Strengthening person-centered care in PHC also requires ongoing, tailored, and context-sensitive educational strategies that promote health literacy, autonomy, and shared responsibility for diabetes management.

The findings also underscore the need to strengthen nurses' role in health education, longitudinal follow-up, and emotional support. They further support the use of relational care strategies grounded in active listening, effective communication, and the development of therapeutic relationships. These strategies can help integrate technical knowledge with people's lived experiences, thereby supporting comprehensive care, improved glycemic control, and quality of life among people with diabetes in communities served by PHC.

Conclusion

The findings indicate that insulin therapy self-management in Primary Health Care is a complex, dynamic, and multidimensional process shaped by emotional, social, and structural factors. Participants initially associated insulin use with fear and resistance. As they developed the knowledge and skills needed for self-management, they gradually reframed insulin as a means of managing their condition and gaining autonomy. Nevertheless, participants continued to face important challenges, including insufficient structured guidance, emotional burden, and difficulty incorporating treatment recommendations into everyday life. These findings underscore the need to reorient care practices by strengthening health edu-

cation strategies, expanding the involvement of the multidisciplinary team—particularly nurses—and incorporating person-centered approaches.

Effective self-management therefore requires ongoing, context-sensitive educational support tailored to individual needs and encompassing technical guidance as well as emotional and social support. Such an approach may help improve glycemic control and promote autonomy and quality of life among people with diabetes.

Authors' contributions

Study conception and design or data analysis and interpretation: **Lira Neto JCG**. Drafting the manuscript or critically revising it for important intellectual content: **Lira Neto JCG, Bezerra MAR**. Final approval of the version to be published and agreement to assume accountability for all aspects of the work, ensuring that any questions related to the accuracy or integrity of any part are appropriately investigated and resolved: **Campos LFR, Lira Neto JCG, Bezerra MAR, Ribeiro IAP, Rocha RC, Nogueira JM, Brito MA**.

Data availability

The dataset supporting the findings of this study will be available from the corresponding author upon reasonable request.

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