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STRUCTURED EDUCATION FOR TYPE 1 DIABETES UNDERSTANDING IN PAKISTAN (SETUP)

Original Research

Dr Atif Munir[1]*, Anum Anwer[2], Dr Sana Ajmal[3]

[1]Consultant Endocrinologist Khairun Nisa Hospital. Assistant Professor Medicine, Fatima Memorial College for Medicine & Dentistry, Lahore, Pakistan. Clinical Adviser and Member Board of Management Meethi Zindagi. FRCP (London, Edinburgh, Glasgow). MRCP Medicine (UK). MRCP Diabetes & Endocrinology (UK). CCT Diabetes & Endocrinology (UK).
[2]Director Peer Support Meethi Zindagi
[3]Executive Director Meethi Zindagi

Corresponding Author: Dr Atif Munir, atif113_2000@yahoo.co.uk, Consultant Endocrinologist Khairun Nisa Hospital. Assistant Professor Medicine, Fatima Memorial College for Medicine & Dentistry, Lahore, Pakistan. Clinical Adviser and Member Board of Management Meethi Zindagi. FRCP (London, Edinburgh, Glasgow). MRCP Medicine (UK). MRCP Diabetes & Endocrinology (UK). CCT Diabetes & Endocrinology (UK).

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ABSTRACT

Background: Type 1 diabetes mellitus is a lifelong condition requiring continuous education, self-management, and psychosocial support to achieve optimal outcomes. In Pakistan, the absence of nationally standardized epidemiological data, limited access to specialist care, and widespread cultural myths contribute to suboptimal disease understanding and management. International structured education programs exist, but they are often poorly aligned with local dietary practices, sociocultural beliefs, and health literacy levels. This gap underscores the need for a locally relevant, evidence-based education framework tailored to the Pakistani context.

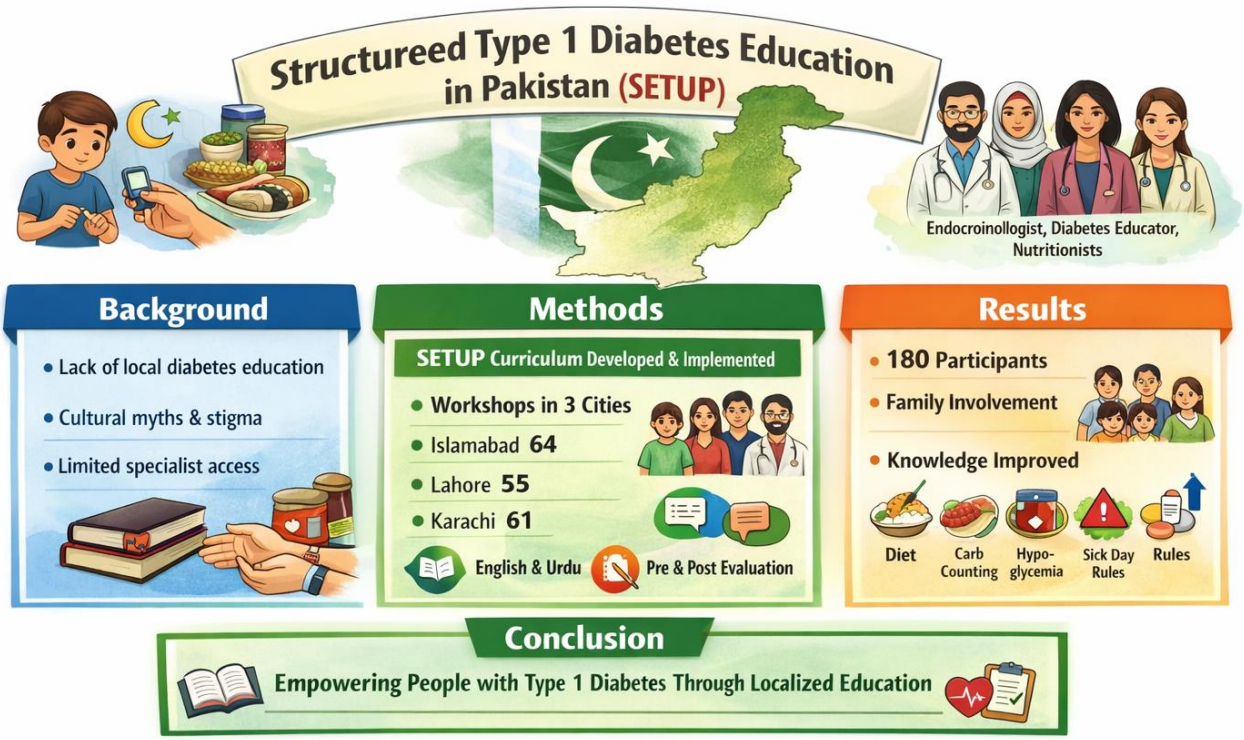
Objective: To develop, implement, and evaluate the feasibility and educational impact of a locally tailored structured education curriculum for people living with type 1 diabetes in Pakistan.

Methods: A multidisciplinary team developed an evidence-based structured education curriculum, Structured Education for Type 1 Diabetes Understanding in Pakistan (SETUP), adapted from international guidelines and refined through local needs assessment and expert peer review. The curriculum was produced in English and Urdu. Curriculum-based interactive workshops were conducted in Islamabad, Lahore, and Karachi. Individuals with type 1 diabetes were enrolled through community networks. Structured pre- and post-session questionnaires and module-wise feedback forms were used to assess changes in participant knowledge and perceived understanding.

Results: A total of 180 individuals with type 1 diabetes participated in the workshops, including 64 from Islamabad, 55 from Lahore, and 61 from Karachi. Most participants were accompanied by a parent or sibling, extending education to family members. Post-session feedback demonstrated consistent improvement in participant knowledge across all core domains, including dietary management, basic carbohydrate counting, hypoglycaemia recognition, and sick-day rules with diabetic ketoacidosis awareness. High acceptability and engagement were reported across all sites.

Conclusion: SETUP proved to be a feasible and well-accepted structured education initiative that effectively improved knowledge among people living with type 1 diabetes in Pakistan. The program offers a scalable, culturally appropriate model for national diabetes education and peer support, with future evaluation planned to assess long-term clinical outcomes.

Keywords: Diabetes Education, Diabetes Mellitus Type 1, Pakistan, Peer Support, Quality of Life, Self-Management, Structured Education



INTRODUCTION

Type 1 diabetes mellitus (T1DM) represents a lifelong autoimmune condition that demands continuous medical care, structured education, and sustained self-management skills to prevent acute and long-term complications. In Pakistan, the true prevalence of T1DM remains uncertain due to the absence of robust national registries and comprehensive epidemiological data; however, the lived experience of individuals with T1DM is frequently shaped by misinformation, cultural misconceptions, and social stigma that directly undermine effective disease management (1,2). Despite advances in insulin therapy and glucose monitoring, outcomes remain suboptimal when individuals and families lack accurate knowledge and confidence to manage the condition in daily life. Healthcare systems in Pakistan face structural constraints, including limited access to trained endocrinologists, uneven distribution of specialist services, and overburdened public-sector facilities (3,4). In this context, people living with T1DM often rely on informal sources of information, where myths related to insulin dependence, dietary restrictions, physical activity, marriage, and fertility persist and remain largely unchallenged. Internationally recognized guidelines emphasize structured diabetes education as a cornerstone of T1DM management; however, these frameworks are predominantly designed for high-resource settings and do not fully account for local dietary patterns, sociocultural beliefs, health literacy levels, or peer-support needs specific to Pakistan (5-7). This mismatch highlights a critical gap between evidence-based recommendations and their practical applicability in local contexts.

Education that is culturally sensitive and locally relevant has the potential to transform disease understanding, enhance self-efficacy, and improve quality of life for individuals with T1DM. A structured curriculum that integrates scientific evidence with local foods, daily routines, cultural norms, and commonly held misconceptions can serve not only as a tool for knowledge transfer but also as a mechanism for empowerment (8,9). Moreover, peer-led education and support platforms have shown value in chronic disease management by fostering shared learning, emotional resilience, and sustained behavioral change, particularly in settings where professional resources are limited. Against this background, the central question guiding this work is whether a locally tailored, structured education curriculum can effectively address prevailing myths, improve disease understanding, and empower people living with T1DM in Pakistan in a manner aligned with international evidence yet grounded in local realities. The objective of this initiative is therefore to develop and implement a context-specific educational framework that raises national awareness, clarifies misconceptions, addresses local needs, and provides a sustainable platform for peer education and support for people living with type 1 diabetes in Pakistan.

METHODS

This work adopted a structured, mixed-methods implementation design focused on curriculum development, expert validation, and nationwide delivery of a locally tailored education program for people living with type 1 diabetes in Pakistan. The project

was conceived, drafted, and executed by Meethi Zindagi, a nationally registered community-based organization led by and for people with type 1 diabetes. A multidisciplinary core team was constituted at the outset, comprising an experienced endocrinologist, a certified diabetes educator, and two nutritionists with specialized expertise in type 1 diabetes management. This team collaboratively conceptualized the project objectives, educational framework, and implementation strategy, ensuring clinical accuracy and contextual relevance throughout the process. An evidence-based structured education curriculum, titled Structured Education for Type 1 Diabetes Understanding in Pakistan (SETUP), was developed through an iterative process. International guidelines and contemporary evidence on type 1 diabetes self-management were reviewed and adapted to local realities, including dietary practices, sociocultural beliefs, health literacy levels, and common misconceptions. The draft curriculum underwent peer review by endocrinologists affiliated with the Pakistan Endocrine Society, experienced nutritionists, certified diabetes educators, psychologists, diabetes advocates, and individuals living with type 1 diabetes from diverse regions of Pakistan. Feedback from these stakeholders was systematically incorporated to enhance clarity, cultural sensitivity, and practical applicability. The finalized curriculum was produced in both English and Urdu to maximize accessibility across varying literacy levels.

Following curriculum development, curriculum-based structured education workshops were organized in three major metropolitan cities—Islamabad, Lahore, and Karachi—to ensure geographic representation and feasibility of implementation. Participants were individuals diagnosed with type 1 diabetes, recruited through Meethi Zindagi's national network and local endocrinology clinics. Inclusion criteria comprised a confirmed diagnosis of type 1 diabetes and willingness to participate in group-based education sessions, while individuals with acute medical instability or inability to provide informed consent were excluded (10,11). Each workshop was facilitated with the involvement of local endocrinologists and trained educators to maintain clinical oversight and consistency in content delivery. Each educational workshop consisted of four interactive modules, each lasting approximately 45 minutes. The modules addressed practical and high-impact domains of daily disease management, including dietary do's and don'ts, basic carbohydrate counting, recognition and management of hypoglycaemia, and sick-day rules with specific emphasis on prevention and early recognition of diabetic ketoacidosis. Teaching methods emphasized interactive discussion, real-life scenarios, and peer engagement rather than didactic instruction alone. At the conclusion of each session, participants received a printed copy of the SETUP curriculum booklet in either English or Urdu, selected according to individual preference, literacy level, and comprehension, to reinforce key learning points and serve as a reference for ongoing self-management.

In addition to face-to-face education, structured peer support was integrated into the methodology as a core component of the intervention. Peer interaction was actively facilitated during workshops, and participants were subsequently enrolled in moderated Meethi Zindagi social media support groups to ensure continuity of education, shared problem-solving, and emotional support beyond the formal sessions. This hybrid delivery model was designed to compensate for limited specialist access and to promote sustained engagement over time. Ethical considerations were addressed in line with standard research and community health practice. Participation was voluntary, and informed consent was obtained from all participants prior to inclusion in the workshops. As the project was implemented as a community-based educational initiative rather than an interventional clinical trial, formal institutional review board approval was not documented; however, confidentiality of participant information and respect for participant autonomy were strictly maintained throughout the program.

RESULTS

The clinical and educational framework of the SETUP curriculum was grounded in internationally recognized, evidence-based guidelines for type 1 diabetes management (3,4). These principles were systematically adapted to the local context through a structured needs assessment derived from feedback collected during Meethi Zindagi's ongoing educational activities across Pakistan. This process resulted in a clearly defined set of curriculum requirements addressing culturally specific dietary practices, prevailing local myths, psychosocial challenges, and coping strategies for living with type 1 diabetes in a society where the condition is often stigmatized. The finalized English version of the curriculum was formally published, and structured education courses were subsequently implemented in three major urban centers of Pakistan, namely Islamabad, Lahore, and Karachi. A total of 180 individuals with type 1 diabetes participated in the SETUP workshops across the three cities. Attendance included 64 participants in Islamabad, 55 in Lahore, and 61 in Karachi. A substantial proportion of participants attended the sessions accompanied by a parent or sibling, thereby extending the reach of the intervention beyond the individual to the family unit and supporting the program's objective of family-centered education and empowerment. Participation was consistent across sites, reflecting broad engagement and feasibility of curriculum delivery in diverse metropolitan settings. Structured pre-event and post-event feedback was collected using standardized questionnaires designed to assess participant knowledge and perceived understanding of key domains covered in the curriculum. Module-specific feedback was also obtained following completion of each interactive session. Analysis of these questionnaires demonstrated a clear improvement in average participant knowledge following completion of the SETUP sessions, indicating effective knowledge transfer across all core curriculum components. Improvements were observed consistently across dietary management, carbohydrate counting, recognition and management of

hypoglycaemia, and application of sick-day rules, including awareness of diabetic ketoacidosis. These findings collectively suggest that the locally tailored curriculum was successful in addressing identified knowledge gaps and reinforcing evidence-based self-management principles.

Table 1: Participant Distribution Across Study Sites

City	Participants with Type 1 Diabetes (n)
Islamabad	64
Lahore	55
Karachi	61
Total	180

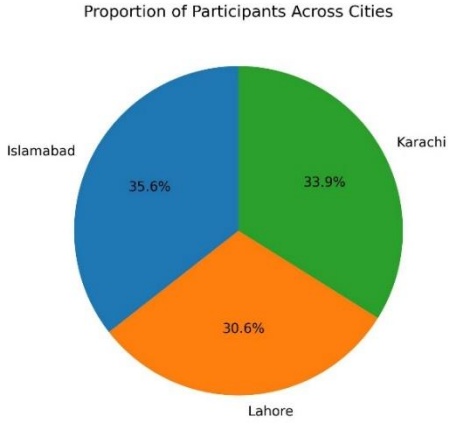
Table 2: Curriculum Coverage and Alignment with Identified Local Needs

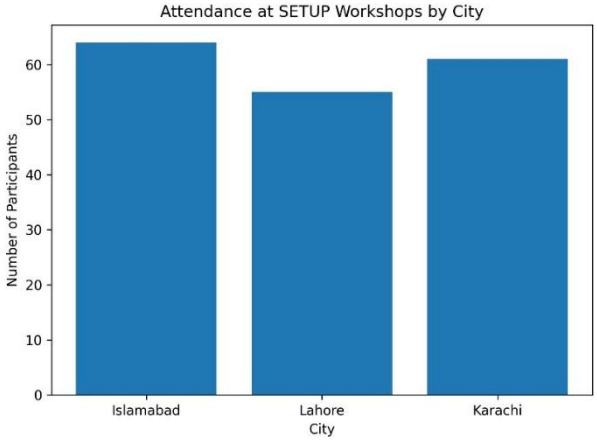
Curriculum Domain	Addressed in SETUP	Mode of Delivery	Objective Alignment
Cultural dietary practices	Yes	Interactive teaching	Education & empowerment
Carbohydrate counting (basic)	Yes	Practical examples	Self-management skills
Hypoglycaemia recognition & management	Yes	Case-based discussion	Safety & prevention
Sick-day rules and DKA awareness	Yes	Scenario-based learning	Acute complication prevention
Psychosocial coping & stigma	Yes	Peer discussion	Myth clarification & support
Peer support mechanisms	Yes	In-person + social media	Sustained engagement

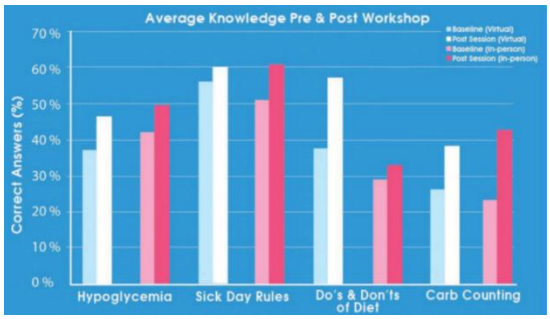
Table 3: Change in Participant Knowledge Following SETUP Sessions (Questionnaire-Based)

Knowledge Domain	Pre-Session Knowledge	Post-Session Knowledge	Direction of Change
Understanding of type 1 diabetes	Lower baseline	Improved	↑
Dietary principles and food choices	Limited	Improved	↑
Carbohydrate counting awareness	Limited	Improved	↑
Hypoglycaemia identification	Variable	Improved	↑
Sick-day rules and DKA awareness	Limited	Improved	↑

Note: Knowledge was assessed using structured pre- and post-session questionnaires.







DISCUSSION

The findings of this initiative demonstrated that a locally adapted, structured education program for people living with type 1 diabetes was feasible, well received, and effective in improving knowledge across core domains of self-management. The observed improvements in understanding of dietary management, carbohydrate counting, hypoglycaemia recognition, and sick-day rules aligned with international evidence indicating that structured diabetes education is a cornerstone of optimal type 1 diabetes care and is associated with better self-management and reduced risk of acute and long-term complications (12-14). By embedding internationally endorsed clinical principles within a culturally sensitive framework, SETUP addressed a critical gap between global guidelines and the realities faced by individuals with type 1 diabetes in Pakistan. Compared with previously reported education models from high-income settings, which often rely on intensive healthcare infrastructure and frequent specialist contact, SETUP demonstrated that community-driven, multidisciplinary education could be successfully delivered in resource-constrained environments without compromising educational depth. The strong engagement observed across all three cities, along with consistent participation by family members, reinforced the importance of family-centered approaches in chronic disease management. This aspect is particularly relevant in collectivist societies, where family attitudes and support strongly influence treatment adherence, psychosocial well-being, and long-term outcomes. The integration of peer support further reflected growing evidence that shared experiential learning enhances self-efficacy and sustained engagement in lifelong conditions such as type 1 diabetes (15-17). A notable strength of SETUP was its rigorous curriculum development process, which combined evidence-based clinical guidance with systematic local needs assessment and broad stakeholder review. The availability of the curriculum in both English and Urdu improved accessibility and inclusivity, while the standardized module structure ensured consistency across sites. Additionally, the involvement of endocrinologists, diabetes educators, nutritionists, psychologists, and people living with type 1 diabetes enhanced the scientific credibility and contextual relevance of the program. The nationwide community response and professional endorsement indicated both acceptability and perceived value within the diabetes and endocrine community (18).

Despite these strengths, several limitations warranted consideration. The assessment of impact relied primarily on pre- and post-session questionnaires measuring knowledge and perceived understanding, without detailed reporting of quantitative scores or statistical significance. Clinical outcome measures, such as glycaemic control, frequency of hypoglycaemia, or hospitalization for diabetic ketoacidosis, were not evaluated, limiting conclusions regarding long-term clinical benefit. Furthermore, the absence of a control group and the short-term nature of assessment restricted causal inference. Selection bias was also possible, as participants were recruited through community networks and may have been more motivated or engaged than the general population of individuals with type 1 diabetes. These limitations highlighted important directions for future research. Longitudinal evaluation using validated, evidence-based questionnaires and objective clinical parameters would strengthen the evidence base for SETUP and allow comparison with international structured education programs. Expansion of the program to rural and underserved regions, incorporation of digital learning tools, and formal integration with healthcare systems could further enhance reach and sustainability. Additionally, systematic evaluation of psychosocial outcomes, family dynamics, and quality-of-life measures would provide a more comprehensive understanding of the program's impact (19-21). Overall, this work suggested that SETUP represented a meaningful step toward addressing long-standing educational and psychosocial gaps in type 1 diabetes care in Pakistan. As the first structured education initiative of its kind for a lifelong condition in the country, it generated momentum, professional support, and community trust. With continued refinement and robust evaluation, SETUP held the potential to serve as a national platform for structured education, peer support, and empowerment, contributing to improved quality of life and more equitable care for people living with type 1 diabetes across Pakistan.

CONCLUSION

This study demonstrated that a locally tailored, structured education program for people living with type 1 diabetes in Pakistan is feasible, acceptable, and effective in improving knowledge across key self-management domains. By integrating evidence-based clinical guidance with cultural relevance, family involvement, and peer support, SETUP addressed critical educational gaps in a resource-limited setting. The initiative highlights the practical value of community-driven structured education as a scalable approach to empower individuals, strengthen self-management, and potentially improve long-term quality of life.

AUTHOR's CONTRIBUTION:

Author	Contribution
Dr Atif Munir	Conceptualization, Methodology, Formal Analysis, Writing - Original Draft, Validation, Supervision
Anum Anwer	Methodology, Investigation, Data Curation, Writing - Review & Editing
Dr Sana Ajmal	Investigation, Data Curation, Formal Analysis, Software

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