

Original Article

Empowerment Through Education: Enhancing the Quality of Life of People with Type 1 Diabetes in Pakistan

Atif Munir,¹ Hamayle Saeed,² Ayma Waqar,³ Anum Anwar,¹ Sana Ajmal¹

¹Meethi Zindagi Pakistan, ²Fatima Memorial Hospital Lahore, ³Lahore Grammar School Lahore

Abstract

Objective: Objective of our study was to assess the quality of life along with the factors influencing it in the Pakistani population with type 1 diabetes. In addition, it also aimed to collate their views about having a national structured education program for empowering people living with type 1 diabetes.

Methods: The study was a cross-sectional and questionnaire based. The results indicated that there is room for improvement in all aspects of health-associated quality of life parameters.

Results: Differences between results across the demographic and clinical domains of subgroups of participants was not statistically significant. 94.9% participants responded positively to the inculcation of a structured education program for type 1 diabetes in Pakistan.

Conclusions: The need for a comprehensive approach to propagate type 1 diabetes understanding in Pakistan is of paramount importance.

Keywords: Type 1 diabetes, quality of life, structured education

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Corresponding Author: Dr. Atif Munir

Email: atif113_2000@yahoo.co.uk

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Introduction

Statistics from the International Diabetes Federation estimate that 1.1 million children and adolescents (under 20 years of age) across the world have type 1 diabetes. Number of newly diagnosed cases of type 1 diabetes worldwide each year is 128,900.¹ Worldwide incidence of type 1 diabetes is increasing but there is a considerable geographic variation in the incidence.¹

Europe has the largest estimated prevalence of people living with type 1 diabetes, total number as it stood in 2019 was 162,600. As per International Diabetes Federation statistics, Pakistan as of 2019 had 1754 people aged 0-19 with type 1 diabetes which appears to be an underestimation considering that Pakistan has an estimated 19.4 million people living with type 2 diabetes.¹ A more recent study puts minimalistic incidence estimate in children under the age of 20 years at 1 per 100,000.¹⁶

Living with a lifelong health condition is expected to have a toll on both physical and mental health in various shapes and forms. This translates into interference with social, personal and professional aspects of life and hence impact quality of life, a pivotal non-medical marker

of wellbeing not widely appreciated as a parameter of health and wellbeing both by the medical fraternity and society in general. However, research evidence to date and people living with diabetes appreciate its significance convincingly.²⁻⁵

Multiple daily blood glucose checks and insulin injections, risk and fear of hypoglycaemia coupled with the long-term health risks are just to name a few things a person with type 1 diabetes has to worry about on a daily basis. Financial restraints, poor health seeking behaviour and social stigma attached with the diagnosis adds to the woes in middle to low income countries like Pakistan.⁶ If all these are coupled with lack of understanding of one's health condition then apart from short and long-term health risks of diabetes a person with type 1 diabetes is left vulnerable to poor quality of life which for a prolonged period of time can lead to poor self-esteem, anxiety and depression. Such consequences can have devastating consequences not just for a person rather a family and for the country as most people living with type 1 diabetes are young, in their formative or productive age group. Assessing quality of life through vali-

dated health questionnaires can allow healthcare professionals to identify needs, modify treatment and offer support in decision making to the people we look after. Structured education is an evidence-based approach which can empower people living with type 1 diabetes to better understand and manage their diabetes hence improving their physical and psychological well-being which can translate into improved quality of life.⁷⁻¹⁰ To date our study is the largest conducted to assess quality of life in people with type 1 diabetes in Pakistan and obviates the need for a structured education program. This study was done to assess the quality of life in Pakistani children and adults living with type 1 diabetes along with factors influencing quality of life and to collate the views of children and adults living with type 1 diabetes in Pakistan about having a national structured education program for educating and empowering people living with type 1 diabetes.

Methods

The study was cross-sectional. The life with type 1 diabetes (Vida con Diabetes tip 1 ViDa1) questionnaire was used.¹¹ This questionnaire was used as type 1 diabetes has a greater impact on life of a person than type 2 diabetes and previously used questionnaires have had their limitations identified with passage of time.¹²⁻¹³

The ViDa1 questionnaire has a list of 34 questions grouped into following four dimensions that shape up health related quality of life. The dimensions included interference with life, self-care, wellbeing and concerns about the medical condition. We added a last question to this questionnaire which was phrased “do you feel a structured education program for type 1 diabetes in Pakistan will empower you to live a better life with type 1 diabetes?”; answer options being a yes or no.

The questionnaire was uploaded on Google forms and the link to participants was shared through Meethi Zindagi’s official Facebook page and closed groups for the type 1 diabetes community (<http://www.facebook.com/meethizindagidiabetes/>). Meethi Zindagi is a duly registered non-profit organization working for the cause of diabetes in Pakistan (www.meethizindagi.org). The Facebook page is a closed group for type 1 diabetes community. Data entry was anonymised. Questionnaire completion & submission was kept open for two months. Parents of young children with type 1 diabetes completed the questionnaire on behalf of their children.

Answers based on a Likert type scale with 1-5 points for each question were added to yield a total score per subject. The questionnaire has no validated cut off points. Statistical analysis was carried out using SPSS version 23. Descriptive statistics i.e., mean and standard deviation were applied. P value of < 0.05 was statistically significant.

Results

A total of 138 participants completed the study questionnaire. 62% were females and 38% were males. Mean age was 24.21 ± 9.02 years. Mean years since diagnosis of type 1 diabetes were 1.39 ± 8.1 years. 70% of participants were studying in universities whilst 30% were school students. Mean most recent HbA1c was 7.97 ± 2.07 %. 62% of participants had no complications of diabetes.

Overall results show that there is a wide scope of improvement in all four dimensions of health-related quality of life. There was no significant statistical difference between quality-of-life dimension results across the demographic and clinical domains of subgroups of participants hence implying that there is scope to improve the quality-of-life parameters across the board for people living with type 1 diabetes in Pakistan irrespective of their age, gender, level of education and duration of diabetes. 94.9% participants feel that having and participating in a structured education program for type 1 diabetes in Pakistan can empower them to improve their diabetes-life balance which can result in improved quality of life.

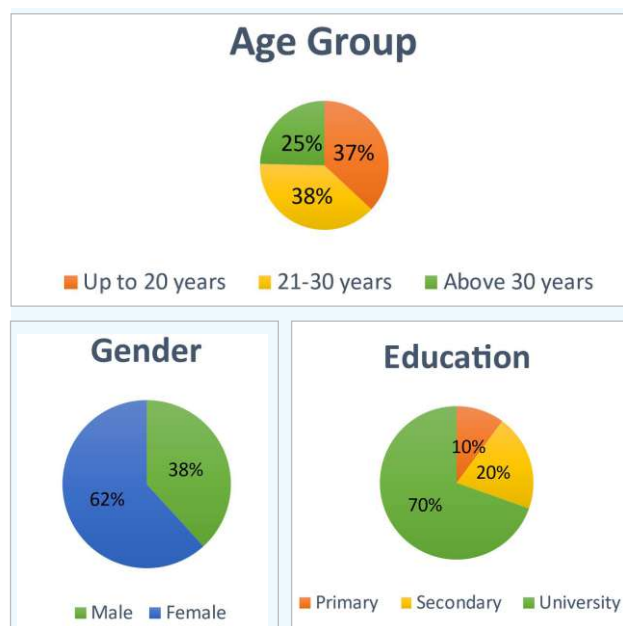


Figure 1: Demographic profile of participants

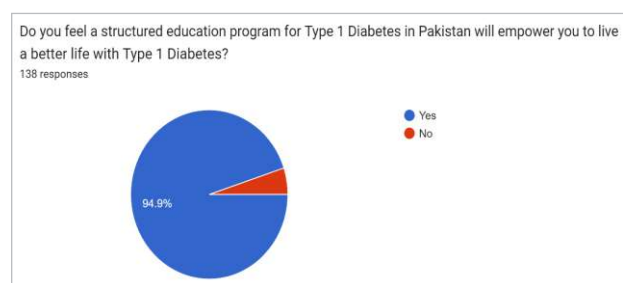


Table 1: Demographic profile of participants

Variable	Number (%)
Age	
Up to 20 years	51
21-30 years	53
Above 30 years	34
Gender	
Male	52 (38%)
Female	84 (62%)
Education	
Primary	14 (10%)
Secondary	28 (20%)
University	96 (70%)

Table 2: Clinical profile of participants

Variable	Number (%)
Years since diagnosis of diabetes	
Up to 5 years	50 (36.2%)
6-10 years	31 (22.4%)
11-15 years	25 (18.1)
More than 15 years	32 (23.1%)
Most recent HbA1c (mean ± SD)	7.97 ± 2.07 %

Discussion

Type 1 diabetes is a lifelong condition with no cure to date. It puts a huge psychological and physical burden on the individual and also affects the family. Financial burden of the condition with Pakistan being a low-income country is worth mentioning. Impact of type 1 diabetes on quality of life and emotional wellbeing usually remains unaddressed in our part of the world due to multiple factors with limited access to specialist health-care, limited understanding of personal health condition and treatment, social stigma, low literacy and high levels of poverty being a few factors of many.

Our study results identify that, there is a major need of culturally tailored, structured education amongst the type 1 cohort of Pakistan. The survey yielded key information and indicated high degree of concern of people with type 1 diabetes towards their daily life including social life and leisure time (eating out, celebrations, travel, etc.). Majority was under the psychosocial pressure of being different from normal individuals of their age, due to type 1 diabetes. More than half of the cohort agreed that type 1 diabetes brings in an additional stress on their daily life. For some of them it's disturbing if others get to know about their condition because of lack of acceptance in society.

The aim of study was to identify the concerns and needs

Table 3: Comparison of demographic and clinical profile of participants across four dimensions of life with type 1 diabetes (Vida con Diabetes tip 1 ViDa1) questionnaire

Participant profile	Dimension				
	Interference with life	Self-care	Well-being	Concern about the illness	Full scale
Age					
≤ 20 years					
Mean	3.00	3.51	3.35	3.93	3.37
SD	0.73	0.71	0.76	0.87	0.51
21-30 years					
Mean	3.20	3.75	3.32	4.01	3.51
SD	0.83	0.71	0.71	0.74	0.46
Above 30 years					
Mean	3.17	3.68	3.30	4.02	3.49
SD	0.80	0.83	0.81	0.62	0.45
P value	0.428	0.164	0.893	0.912	0.127
Sex					
Male					
Mean	3.26	3.75	3.41	3.20	3.56
SD	0.84	0.72	0.75	0.74	0.43
Female					
Mean	3.01	3.56	3.26	3.96	3.37
SD	0.73	0.76	0.74	0.78	0.49
P value	0.05	0.11	0.28	0.93	0.05
Education Primary					
Mean	3.0	3.5	3.45	3.86	3.37
SD	0.93	0.98	0.93	1.10	0.81
Secondary					
Mean	3.16	3.54	3.31	3.83	3.41
SD	0.75	0.68	0.75	0.86	0.47
University					
Mean	3.12	3.69	3.31	4.04	3.48
SD	0.78	0.73	0.73	0.67	0.42
P value	0.93	0.44	0.62	0.51	0.31
Years since diagnosis of diabetes					
≤ 5 years					
Mean	3.16	3.53	3.26	3.84	3.40
SD	0.75	0.79	0.76	0.93	0.50
6-10 years					
Mean	2.85	3.92	3.49	3.88	3.46
SD	0.76	0.57	0.61	0.66	0.40
11-15 years					
Mean	3.14	3.73	3.55	4.11	3.55
SD	0.85	0.65	0.66	0.68	0.38
>15 years					
Mean	3.29	3.49	3.11	4.14	3.45
SD	0.77	0.83	0.86	0.58	0.58
P value	0.10	0.09	0.09	0.41	0.53

SD = Standard Deviation

of the people living with type 1 diabetes before an education program is implemented. It included not only people with the condition but also family members specifically parents of children with type 1 diabetes. Aspects including implication, self-management, and psychological support were highlighted.

The results highlight the wide scope of improvement in all quality-of-life domains and that this scope exists across all people with type 1 diabetes in Pakistan irrespective of their level of age, sex, education and duration of diabetes. There are no validated cut-off points for the questionnaire and its interpretation is based on mean scores but the study clearly highlights that most people living with type 1 diabetes feel that a national structured type 1 diabetes education program in Pakistan is the need of the hour to empower them to live a better life with type 1 diabetes. From data available, structured type 1 diabetes education programmes not only improve clinical parameters like HbA1c which if sustained can reduce complications of type 1 diabetes hence improving morbidity and mortality from such complications but also improve psychological distress from type 1 diabetes and improve perceived wellbeing.^{10,14,15} This study can also sensitize physicians for behavioural and psychological monitoring of people living with type 1 diabetes.

Although children and adolescents living with type 1 diabetes have to live with a demanding lifelong treatment regime, overall results revealed that there is a huge need of structured program that can be helpful to educate about self-management and empower them to deal with psychosocial pressures without being under stress due diabetes-related worries. Longitudinal research is needed to understand and provide tailored care for all ages.

Conflict of Interest: *None*

Funding Source: *None*

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