RESEARCH ARTICLE

COGNITIVE AND FAMILY DYNAMICS IN ADHERENCE TO THE TREATMENT AMONG ADOLESCENTS WITH TYPE 1DIABETES

[1,] *Sanjana Malhotra and [2]Sherin P. Antony

[1]Department of Psychology, Jain University, Bangalore, Karnataka State, India
[2]Department of Psychology, Acharya Institute, Bangalore, Karnataka State, India

ARTICLE INFO	ABSTRACT

Aim: To analyse the potential cognitive factors and family functioning related to adherence among type 1 diabetic mellitus adolescents in India.

Method: Standardised tools such as Hospital Anxiety and Depression Scale (1983); Self Care Inventory-R(2001); Emotional Regulation(2003); Family Assessment Device(1983) was administered on 84 adolescents who had mean age of 15.4 years; their age of diabetes onset was 9.83 years; the mean duration of diabetes mellitus was 5.5 years; 37% boys were participants in the current study and 52% of the participants hailed from urban and semi-urban areas.

Results: The results were analyzed through the statistical tool Spearman correlation which revealed significant relationship between family functioning and adherence ($p=.318**$); behavioural control practiced by family members and adherence ($p=.339**$); affective involvement and adherence ($p=.216*$); communication and adherence ($p=-.261*$).Thus, when an individual is able to evaluate their family environment, they are more likely to adhere to their treatment regimen.

Conclusion: A chronic health condition may likely place the adolescent in jeopardy for developing emotional and behavioural problems which may hinder adherence to treatment regimen. Also, the functioning of the family in which the adolescent resides can influence adherence to the diabetes regimen.

INTRODUCTION

Diabetes is a chronic disorder which requires constant care that can be distressing for the individual afflicted with the health condition as well as the care-givers. Diabetes mellitus is a metabolic disorder characterized by chronic hyperglycaemia resulting from insulin resistance. It is an endocrine disorder caused when the pancreas in the body either produce little or no insulin. Pancreas, a digestive gland releases the chemical known as insulin into the bloodstream which transports glucose to each cell of the body to generate energy and balances blood sugar levels to avert long-term health complications which can be fatal for survival. Thus, insulin is a life benevolent hormone. According to the International Diabetes Federation Atlas, despite type 1 diabetes being the least frequent, it is amplifying by around 3% each year, specifically among children. Approximately 86,000 children develop type 1 diabetes every year and the absence or shortage of insulin supply lowers the life expectancy for the child along with adding health complications to their life.

*Corresponding author: Sanjana Malhotra
Department of Psychology, Jain University, Bangalore, Karnataka State, India.

In the South- East Asian region which comprises India, the estimated number of children living with type 1 diabetes (0-14 years) is 81,400 in 2015 and the numbers of newly diagnosed children in 2015 were 13,100. In India, the Karnataka state T1DM registry listed an incidence of 3.7/100,000 in boys and 4.0/100,000 in girls over 13 years of data collection (Results from Karnataka Diabetes Registry 1995-2008). International Society for Paediatric and Adolescent Diabetes (ISPAD) Consensus Guidelines 2000 stated that "Psychosocial factors are the most important influences affecting the care and management of diabetes". Since, a person's individuality is characterised by their perspectives, thoughts and society, human contact influences a person in several ways. The everyday challenges faced by diabetic adolescents in terms of taking insulin, adjusting the insulin dosage, eating meals at a scheduled time, appropriate exercise along with their daily chores which includes going to school or college, handling academic work and extra-curricular activities and socialising with friends can influence their ways of coping with their diabetes regimen. Since, adolescence is a phase in which they are developing independence from their parents, desiring peer acceptance, experiencing hormonal changes, the transition of becoming an adult comes with challenges which is linked to

reduced adherence to treatment regimen, decline in metabolic control and psychosocial issues (Salerno *et al.,* 1997). During their course of managing this lifelong health condition, adolescents can face anxious moments which may give them stress, extreme worry, feelings of helplessness and lowness that can lead to depression and possibly may exhaust them of the self-care behaviour they have to adhere to day-in and day-out. Research results demonstrate that poor metabolic management is associated with numeral psychosocial issues that include anxiety, depression and poor self-esteem. However with continuation of psychosocial and emotional adjustment problems into late adolescence signify larger threat for poor diabetes management in early adulthood adolescents (ISPAD Clinical Practice Consensus Guidelines, 2009).

Thus, the varied ways employed to cope with the health condition and how the individual emotionally regulates the effect is significant for the metabolic control along with adherence to the medical regimen that is a necessity to be followed to keep at bay complications associated with diabetes such as nerve damage, adverse effects on heart, kidney, eyes and liver. Since diabetes affects not only the afflicted but the family is also affected in terms of organising events or planning around the needs of the child and overseeing whether the child is adhering to the prescribed regimen. Adherence to managing diabetes is independent of gender (Pattino AM, Sanchez J, Edison M, Delamater AM, 2005; Naar-King S *et al.,* 2006). Enhancement in adherence is optimistically correlated with variables such as coping, self-efficacy, family functioning and psychosocial modification metabolic organization (Graue, Wentzel-Larsen, Bru, Hanested and Sovik, 2004; Grey, Lipman, Cameron and Thurber, 1997; Griva, Myers and Newman, 2000). Adherence refers to determine the disease management activities as directed by the health professional. Non-adherence has been recognized as an invasive threat to health and welfare of an individual in addition to posing an economic burden too. Most visits to a medical centre are due to poor adherence which is the chief reason of poor health (Zolnierek, DiMatteo, 2009).

Aim and Objective

The aim of the current research is understand the relationship between cognitive factors and adherence and family functioning and adherence in order to come across the factors that can increase or decrease the level of obedience to regimen that diabetic adolescents have to follow since it can show the way where intervention is required and can be beneficial to the patients to aid them in adhering to their regimen. The objectives are twofold: firstly, to determine if there is a relationship between the cognitive variables and adherence, namely anxiety, depression, cognitive reappraisal and expressive suppression and secondly to determine if there is a relationship between family functioning and adherence wherein six aspects of family functioning were correlated to observe if there is any association.

MATERIALS AND METHODS

The current study engaged a correlational research design carried out in the state of Karnataka, India. The source of data was patients visiting hospitals and clinic and who had onset of diabetes since more than one year. Following approval from the Institutional Ethics Committee and consent from parents and assent from adolescents, 84 adolescents participated in the study voluntarily through purposive sampling method since the criterion for participation included adolescents from the age range of 10-19 years and excluded patients who had an accompanying chronic disease or psychiatric illness.

Tools

Gathering of data commenced with taking the socio-demographic and clinical details followed by administration of paper-pencil tests which comprised standardised questionnaires such as:

Hospital Anxiety and Depression Scale (1983): This scale has been developed by Zigmond and Snaith, to identify states of anxiety, depression and emotional distress among patients being treated for clinical problems. The scale has 14 items scores on a scale of 0-3 with 3 representing increased frequency of symptoms and it can be self-assessed. The scores for the two subscale- anxiety and depression range from 0-21 with categorical divisions of normal, mild, moderate and severe. The overall scale indicates emotional distress. The second tool is the Self Care Inventory-R (2001), which is a self-report evaluation that measures the perception of patient's adherence to diabetes self-care regimen. It assesses four elements of behaviour related to adherence, namely monitoring, diet, insulin and exercise. The scoring is on a 1-5 scale having 15 items, with higher scores revealing more t favourable adherence.

The third tool is Emotional Regulation (2003) which is a questionnaire developed by Gross, J.J., O.P. designed to gauge the inclination of respondents to regulate emotions in either of the two ways: cognitive reappraisal and expressive suppression. It is measured on a 7 point likert scale. *Cognitive reappraisal* is defined as the effort to reconstruct a situation that brings out emotions in a technique that amends its meaning and modifies its impact. (Lazarus and Alfert, 1964; Gross and John, 2003). *Expressive suppression* is defined as the endeavour to conceal, restrain or decrease ongoing emotion-expressive behaviour (Gross and Levenson, 1993; Gross and John, 2003). The fourth tool is Family Assessment Device (1983) developed by Nathan Epstein, Lawrence Baldwin, and Duane Bishop which assesses the structural, transactional and organisational attributes of families. It comprises 6 subscales- affective involvement, affective responsiveness, behavioural control, communication, problem solving, and roles. These subscales comprise in totality 60 statements scored from 1-4 and higher scores depict worse intensity of family functioning. Once the data was collected, it was inferred by means of Spearman's rho and results were considered significant when p-value was <0.05.

RESULTS

The study involved 84 participants having type 1 diabetes since more than one year with mean age of 15.4 years. There were 37% boys and 63% girls who were participants to the current study and 52% of them belonged to urban and semi-urban cities within the State. The mean age of onset of diabetes in the participated group is 9.8 years and the mean duration of being affected with diabetes mellitus is 5.5 years. Analysis of relationship between cognitive variables and adherence was carried out using non-parametric test, Spearman's rho correlational test at 2-tailed significance level.

Table 1. Socio-Demographic Characteristics

Characteristics	Summary of statistics
Gender:	63%
Girls	37%
Boys	
Place of residing:	
Urban and Semi-urban	52%
Rural	48%
Age	M=15 years4months
Age of onset	M= 9years 8 months
Duration of living with diabetes	M=5 years 5 months

Table 2. Relationship between Cognitive Variables and Adherence

Spearman's rho	Anxiety	Depression	Emotional Distress	Cognitive Reappraisal	Expressive Suppression
Adherence Correlation Coefficient	.186	.059	.125	.067	-.011
Sig.(2-tailed)	.090	.596	.258	.547	.919

Table 3. Relationship between Family Functioning and Adherence

Spearman's rho	Family Functioning (on the whole)	Affective involvement	Affective responsiveness	Behavioural control	Communication	Problem solving	Roles identified in the family
Adherence Correlation Coefficient	.318**	.216*	.042	.339**	-.261*	.048	.105
Sig.(2-tailed)	.003	.048	.703	.002	.016	.665	.340

$**p<0.01$; $* p<0.05$

The results did not reveal any significant relationship between the cognitive variables and adherence. Investigation of relationship between family functioning and adherence was carried out by means of non-parametric test, Spearman's rho correlational test at 2-tailed significance level. The results revealed strong significant relationship at 0.01 level between family functioning on the whole which refers to the structure, administration and agreement within the family members with adherence to the treatment regimen that diabetic adolescents have to follow; between behavioural control and adherence which conveys that there is an influential relationship between the way the family puts across and sustains standards for the behaviour of its members with the obedience to the treatment regimen that has to be followed. Significant relationship at 0.05 level was observed between affective involvement and adherence suggesting that adherence or loyalty to the diabetic adolescent's is influenced by the degree to which their family members are concerned and place importance in their activities. Lastly, inversely significant relationship at 0.01 level was seen between adherence and communication proposing that the lesser the amount of information exchanged within the family, the more will be the adherence by the adolescence. Therefore, if the adolescents are not told what to do or what to avoid all or most of the time by all the family members, they are further prone to be faithful to carrying out their self-care activities.

DISCUSSION

In the present research, no relationship was found between cognitive variables and adherence which is inconsistent with the literature that states that adolescents with diabetes emerge to be significantly at risk for developing depression especially one episode of depressive disorder or anxiety before entering into adulthood (Kovacs *et al.,* 1997; Lawrence *et al.,* 2006) and also it was observed that the two components of emotional regulation was not related to adherence which additionally refers to being obedient and taking responsibility to manage their treatment routine which requires the adolescent to be autonomous and accept their health condition.

However, this result too has been inconsistent with the research findings from other studies that state that cognitive reappraisal was linked with elevated self-esteem, self-acceptance, coping strategies, improved interpersonal relationships and enhanced autonomy and the ability to master the environment whereas expressive suppression was completely inverse (John and Gross, 2004, Sheldon *et al.,* 1997). This explanation of this result can possibly be the scale employed to assess adherence in participants, since it was a self-report measure to determine the self-care activities carried out by the adolescents themselves. It was observed that family functioning had a strong influence on adherence or obedience to the schedule that should be followed for appropriate self-care. Particularly, behavioural control and affective involvement which yields that the manner in which the family conveys, sets principles and is involved and engaged with erstwhile family members, the loyalty to the diabetic management routine is present. These results are consistent with findings from a similar study that assesses the glycemic control, family functioning and adherence of children having type 1 diabetes which divulges that family cohesion protects against poor health outcomes in diabetes (Cohen, Lumley, Naar-King, Partridge and Cakan, 2013) and also reliable with conclusions from studies on diverse health problems such as paediatric inflammatory disease, kidney disease (Burke, Neigut, Kocoshis, Chandra and Sauer, 1994; Soliday, 2001).

Limitations

This was a correlational study; therefore predictor variables could not be identified. The study was carried out in a clinical setting in a single State, thus sampling from diverse setting and places can advance the precision of the results.

Conclusion

The study establishes that family functioning is an imperative variable to increase or sustain the adherence to diabetes self-care regimen. The study emphasises that excessive communication with the adolescent about how they are

managing diabetes, questioning them or telling them what is to be done, can lower the adherence level which can lead to unfortunate health outcomes since adolescents are in the stage where they require autonomy. Thus, setting certain principles and values in the family and involving all the family members in the same can lead to the diabetic adolescence to obey their treatment regimen since they see each member following certain principles that have been set in the family.

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