

ORIGINAL ARTICLE

The Relationship Between Compliance and Quality of Life among Adolescents with Diabetes Mellitus Type 1

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ABSTRACT

Objectives: This research aimed at investigating the relationship between compliance and quality of life among adolescents with diabetes mellitus type 1 (DMT1). The study explored the impact of an information giving intervention on compliance and quality of life in adolescents with DMT1 and factors related to compliance and its effect on the quality of life.

Methodology: This study was a randomised control trial, with an intervention and wait list control group. In this study, data was collected from participants aged 16 to 19 years.

Main outcomes: Compliance to treatment, impact about diabetes and worries about diabetes were highly significant at follow up in the intervention group and seemed to have had impacted positively in the lives of the adolescents and also influenced positive behaviour change to the treatment regime prescribed to them by the doctors. This indicated that there was a relationship between compliance and quality of life among adolescents with diabetes mellitus type 1.

Measures: Instruments used by the researcher at both pre intervention and post intervention periods included: Social demographic questionnaire, the rating scale for compliance (RSC) and Diabetes Quality of Life Scale modified for youths (DQOL)

Procedure: Permission was obtained from the study site. Approval was obtained from Research Ethics committee, University of Zambia.

The baseline measures for intervention and control group was done in week 1 (time 1), where the 40 adolescents answered the demographic questionnaire, quality of life

scale modified for youths and the rating scale for compliance. In week 2 to week 9, the researcher was with the intervention group and had 1 meeting with them once in a week. In week 10; time 2, follow up measure (same used at time 1 with intervention and control group) was done. The researcher met both groups at the Diabetes Association of Zambia Centre DAZ in University teaching hospital UTH. The participants were asked to complete the demographic questionnaire, rating scale for compliance and the diabetes quality of life scale modified for youths. These questionnaires were completed one after the other in both baseline intervention and follow up (post assessment). Instructions were read to them before they started answering each questionnaire in a plenary setup.

Results: The demographic results indicate an even distribution of participants by age in both the control and intervention groups. The results showed that there was a significant difference between the control and intervention group at follow up in compliance to treatment were $P = .000$, impact of diabetes $P = 0.045$ and worries about diabetes $P = .001$. However, satisfactions with life showed a significant difference between the control and intervention group at follow up were $p = .000$, the control group showed more satisfaction with life compared to the intervention group at follow up.

Conclusion: The information that the adolescents received during the intervention period seemed to have had impacted positively in the lives of the adolescents and also influenced positive behaviour change to the treatment regime prescribed to them by the doctors.

Key words: Adolescents, diabetes, compliance, quality of life

INTRODUCTION

Diabetes mellitus is a chronic condition affecting approximately 285 million people in the world and the figure is expected to rise by more than 50% in the next twenty years (Novato and Gross, 2009). **Diabetes mellitus** is now one of the most common non-communicable diseases globally. It is the fourth or fifth leading cause of death in most high-income countries and there is substantial evidence that it may be an epidemic in many economically developing and newly industrialized nations (IDF, 2009). Complications from diabetes, such as coronary artery and peripheral vascular disease, stroke, diabetic neuropathy, amputations, renal failure and blindness are resulting in increasing disability, reduced life expectancy and enormous health costs for virtually every society. Diabetes is undoubtedly one of the most challenging health problems in the 21st century (IDF, 2009). Diagnostic investigations done to confirm the disease include blood and urine testing for sugar. Urine is obtained and tested for the odour, colour, gravity and clintext reaction. Blood is also tested for postparadial blood glucose and glucose tolerance (Obasi, 2006).

Diabetes occurs when the body cannot produce enough or effectively use insulin (IDF, 2009). Insulin is a hormone which is manufactured in the pancreas, the insulin levels in blood vary with the amount of glucose present in the blood. Diabetes is a condition that makes it difficult for the cells of the body to get adequate amount of glucose (Obasi,

Zambian prevalence

There are few detailed studies on diabetes in Zambia, the estimates of prevalence and prognosis in Zambia was estimated at that of 12.0 per hundred populations, these figures compare with estimates of type 1 diabetes mellitus prevalence by the International Diabetes Federation of 4.8 per hundred thousand (Baren et al. 2005). However, the higher priority of diabetes care in national health care planning in Zambia maybe attributed in part, to the active advocacy and educational role played by Diabetic Association of Zambia (DAZ). The international diabetes federation further estimates the prevalence of diabetes in Zambia at 3.1% globally and that diabetic retinopathy is responsible for 4.8% of all

blindness (Kaseba, 2012).

Pathogenesis, Aetiology and Symptoms of Diabetes Mellitus type 1

Pathogenesis of IDDM is precipitated by environmental factors in a genetically susceptible individual and damage to cells is autoimmune mediated. Type 1 diabetes is a condition in which pancreatic cell destruction usually leads to absolute insulin deficiency. Insulin directly regulates the rate of carbohydrates metabolism and directly influences fat and protein metabolism (Daneman, 2006).

Consequently insulin deficiencies due to beta cell damage result into overwhelming stress and inevitably triggers a chain reaction of unwanted events. First of all insulin is not conveyed from the extra cellular fluid into the intracellular compartment (Obasi, 2006). Without glucose, the cells become deficient in energy to oxidize fats and protein. The energy is then drawn from adipose tissue and muscles store. The resultant breakdown of fat or protein causes tissue wasting and fat breakdown. Glucose which is locked outside the cells without the insulin begins to accumulate and eventually raise the blood sugar level (hyperglycaemia) (Court et al., 2009).

Diabetes and adolescents

Diabetes can affect an adolescent's emotions both directly and indirectly. Poorly controlled blood sugar can directly affect the emotions by causing behaviour changes, such as irritability. Adolescents with diabetes have an increased risk of depression and anxiety, which may be why many diabetes specialists include a social worker or psychologist as part of their diabetes care team (Battista et al., 2009). This may interfere with behavioural and quality of life among adolescents with type 1 diabetes mellitus. pushing adolescents too hard to autonomy may lead to serious problems and adolescents who assume diabetes responsibilities too soon face an increased risk of problems with treatment adherence, poor metabolic control and intermittent hospitalizations (Frank, 2005).

Moving toward independence from their parents, adolescents typically want to make their own choices and have a sense of control over their lives. Having a disease may make them feel powerless and they try to gain

control by not taking medications, missing appointments or not following dietary restrictions (Health information, 2012). Sometimes, the parents may have developed an overprotective parenting style, which can delay the teen's ability to take responsibility for his or her treatment or cause frustration for the adolescent. Thus, low compliance can be a way of confronting the authority of parents and professionals (Taddeo, 2008). Adolescents in particular, may have a particularly hard time dealing with diabetes. A child who has been very good about sticking to his or her diabetes regime may rebel in the teen years by ignoring his or her diabetes care plan.

Adolescents with diabetes tend to ignore their vulnerability to potential consequences of their disease in their age appropriate preoccupation with the present (Guthrie, 2003). They may also experiment with drugs or alcohol, behaviours that can be even more dangerous for someone with diabetes. Eating disorders and forgetting insulin doses are other problems that can occur more often in the adolescent years (Health information, 2012).

Psychological factors associated to adolescents with diabetes mellitus type 1 on Treatment compliance

Metabolic control deteriorates in adolescents when compared with children and adults. This can be explained by the physiological changes, insulin resistance and compliance problems that occur with puberty which seem to be high in adolescence (Frank, 2005). The psychological factors that account for poor treatment compliance is best understood within the context of normal adolescent development. Experimentation rebellion and risk taking are often associated with the adolescent' struggle for control of their destiny. This is a challenging time for adolescents, parents and health professionals (Frank, 2005). Treatment compliance among adolescents with type 1 diabetes mellitus is low in 50% of diabetic teenagers and this is becoming a social and medical problem (Frank, 2005).

Importance of compliance

Many diabetic patients work to manage the health complications with diet and exercise; they also require medications to improve abnormal and uncontrolled blood glucose levels (Obasi, 2006).

Compliance is the number one factor that determines a healthy outcome in the diabetic patient (Cadena, 2007). Compliance also help patients to take control of their situations with focus on maintaining emotional and physical health. Noncompliance with diabetes treatment regime can lead to life threatening complications (Novato and Gross, 2009).

METHODS

Study design

This study was a randomised control trial, with a wait list control. The study utilised a cross sectional study design. In this study, data was collected from participants aged 16 to 19 years. The participants were assessed using the Rating Scale for Compliance authored by Clark & Goosen (2005). This scale tested adolescents using four factors namely insulin, diet, exercise and hypoglycaemic episodes, these determined the frequency of insulin intake, taking recommended food, time and frequency of exercise and clinical history of diabetes episodes. Additionally, the Diabetes Quality of Life Rating Scale authored by Jacobson et al., (1988) designed for youths was used to assess the impact of diabetes, worries about diabetes, satisfaction with life.

Study setting

This study was conducted at the University Teaching Hospital (UTH) Lusaka. Diabetes association of Zambia Centre (DAZ).

Study Sample

A total of 40 adolescents with diabetes mellitus type 1 who were diagnosed within the past 6 months at the time of recruitment because they are adjusting to the disease were recruited in the study. The sample was in the age range of 16 to 19.

Procedure

The baseline measures for intervention and control group was done in week 1 (time 1), where the 40 adolescents answered the demographic questionnaire, quality of life scale modified for youths and the rating scale for compliance. In week 2 to week 9, the researcher was with the intervention group and had 1 meeting with them once in a week. In week 10; time 2, follow up measure (same

used at time 1 with intervention and control group) was done. The researcher met both groups at the in University teaching hospital UTH DAZ center. The participants were asked to complete the demographic questionnaire, rating scale for compliance and the diabetes quality of life scale modified for youths. These questionnaires were completed one after the other in both baseline intervention and follow up (post assessment). Instructions were read to them before they started answering each questionnaire in a plenary setup.

Data analysis

Descriptive analysis was used to obtain means for the independent and dependent variables using scientific package for Social Sciences (SPSS) 16.0 for windows. Mann Whitney U test was used to explore the impact of an information giving intervention, effects of compliance on the daily living of adolescents with type 1 diabetes mellitus and the factors related to compliance were also explored. The bivariate correlation coefficient was also done to test the hypothesis that there was a positive correlation between compliance and quality of life among adolescents with diabetes mellitus type 1. The demographic characteristics of adolescents were also analysed using descriptive analysis.

RESULTS

The background information about the participants descriptions of demographic characteristics of the sampled adolescents indicated that; in the control group 11 (27.5%) adolescents were males while 9 (22.5%) were females. In the intervention group 11 (27.5%) adolescents were males and 9 (22.5%) were females. With regard to age; the control group had 7(17.5%) adolescents aged 16-17 years and 13 (32.5%) adolescents aged 18-19 years. While the intervention group had 7(17.5%) adolescents aged 16-17 and 13 (32.5%) adolescents aged 18-19 years.

Compliance to treatment

The individual items of compliance scales were analyzed using descriptive statistics in order that participants responses are shown with their specific responses to scales of compliance, this gives a summary of findings on the levels of compliance to treatment between the control

and intervention groups at baseline and follow up. The items measured for compliance included: time at which insulin is taken, units of insulin, delay in meal timings, and lapse in diet, physical exercises and hypoglycemic episodes. Before looking at the total score for compliance for the control and intervention group at the two time points (baseline and follow up), a descriptive analysis was carried out on each item of the scale to look at the trend for compliance.

Time at which insulin is taken results showed that a large number of adolescents (100%) in the follow up intervention group took insulin on time on all the days compared to the control group. Therefore this is an indication that compliance levels improved among adolescents after the information giving intervention in the follow up intervention group.

The units of insulin change results suggested that the adolescents in the follow up intervention group made no change to their insulin dosage other than what the doctor would make. They complied to the treatment that was given to them without making any change of their own hence all the adolescents (100%) appreciated following doctors prescriptions leading to high compliance to insulin.

Delay in meal timings results suggested that adolescents in the follow up intervention group appreciated taking their meals on time because they learnt the importance of taking meals on time to maintain their energies during intervention. Therefore all the adolescents (100%) in the follow up intervention group had high compliance to taking meals on time.

Lapse in diet shows that; These results suggest that adolescents in the intervention group at follow up experienced no lapse in diet. These adolescents might have appreciated the importance of taking the correct food prescribed by the doctors. Therefore the intervention group at follow up (75%) highly complied to their prescriptions. Hence they had no laps in diet.

Physical exercises results suggested that all the adolescents (100%) in the intervention group at follow up appreciated exercises as part of their treatment. Adolescents exercised at least five times in a week to strengthen their bodies. Therefore, compliance to exercises was high in the intervention group at follow up.

Hypoglycemic episodes results suggested that the intervention group at follow up (100%) experiences no frequency of hypoglycemic episodes. These adolescents might have been compliant to the treatment prescriptions given to them by the doctors. Therefore there was high compliance were all the adolescents in the intervention group at follow up had no frequency of hypoglycemic episodes.

A Mann Whitney U test was conducted to establish whether there was a difference between the control group and the intervention group at baseline and follow up on compliance to treatment.

The table 1 below shows the results for compliance to treatment. The mean for the control group at baseline was 14.60 while that for the intervention group was 26.40 with a Z value of -3.416 (p= .001). This indicates that at baseline, there was a significant difference between the control and intervention group.

At follow up, the mean score for the control group was 30.00 and that for the intervention group was 11.00 with a Z value of -5.570 (p= .000). Therefore there was a significant difference between the two groups at the follow up time. Lower score indicates more compliance to treatment. The compliance in the intervention group seems to have improved at follow up than baseline.

Table 1: Compliance to treatment

Compliance to treatment	Time	Control group mean (n=20)	Intervention group mean (n=20)	Z	P value
	Baseline	14.60	26.40	-3.416	.001
	Follow up	30.00	11.00	-5.570	.000

Impact of diabetes

The impact of diabetes on adolescents with diabetes mellitus type 1 was assessed. A Mann Whitney U test was conducted to establish whether there was a difference between the control group and the intervention group at baseline and follow up.

The table 2 below shows the results on impact on diabetes. The mean score for impact on diabetes in the control group at baseline was 17.8 while that for the intervention group was 23.2 with a Z value of -1.47 (p= 0.14). This indicates that at baseline, there was no significant difference between the control and intervention group.

At follow up, the mean score for impact on diabetes for the control group was 24.2 and that for the intervention group was 16.8 with a Z Value of -2.00 (p= 0.045). Therefore there was a significant difference between the two groups at the follow up time. Lower score indicates lower impact of diabetes. Therefore the intervention group seems to have less impact of diabetes compared to the control group on the follow up time.

Table 2: Impact of diabetes

Impact of diabetes	Time	Control group mean (n=20)	Intervention group mean (n=20)	Z	P value
	Baseline	17.8	23.2	-1.47	0.14
	Follow up	24.2	16.8	-2.00	0.045

Worries about diabetes

The adolescents' level of worries about diabetes was also assessed. A Mann Whitney U test was conducted to establish whether there was a difference between the control group and the intervention group at baseline and follow up. The table 3 below shows the results on worries about diabetes. The mean score for the worries about diabetes in the control group at baseline was 22.35 while that for the intervention group was 18.65 with a Z value of -1.018 7 (p= .309). This indicates that at baseline, there was no significant difference between the control and intervention group.

At follow up, the mean score for worries about diabetes for the control group was 26.68 and that for the intervention group was 14.32 with a Z value of -3.353 (p = 0.01). Therefore there was a significant difference between the two groups at the follow up time. Lower score indicates fewer worries about diabetes. Therefore the intervention group seems to experience fewer worries about diabetes compared to the control group at the follow up time.

Table 3: Worries about diabetes

Worries about diabetes	Time	Control group mean (n=20)	Intervention group mean (n=20)	Z	P value
	Baseline	22.35	18.65	-1.018	.309
	Follow up	26.68	14.32	-3.353	.001

Satisfaction with life

Satisfaction with life was assessed. A Mann Whitney U test was conducted to establish whether there was a difference between the control group and the intervention group at baseline and follow up.

The table 4 below shows the results on satisfaction with life. The mean score for satisfaction with life for the control group at baseline was 22.42 while that for the intervention group was 18.58 with a Z value of -1.057(p = .290). This indicates that at baseline, there was no significant difference between the control and intervention group.

At follow up, the mean score for satisfaction with life for the control group was 12.50 and that for the intervention group was 28.50 with a Z value of - 4.394 (p = .000). Therefore there was a significant difference between the two groups at the follow up time. Lower score indicates more satisfaction with life. Therefore the control group seems to experience more satisfaction with life compared to the intervention group at follow-up time.

Table4: Satisfaction with life

	Time	Control group mean (n=20)	Intervention group mean (n=20)	Z	P value
Satisfaction with life	Baseline	22.42	18.58	-1.057	.290
	Follow up	12.50	28.50	-4.394	.000

A bivariate correlation coefficient test was conducted at follow up to test the hypothesis that there was a positive correlation between compliance and quality of life at a significance level of 0.01. The results were $r = 0.468$; $p = 0.002$. The table 5 below shows the results. Since the significance level was less than 0.01 the alternative hypothesis was accepted. Therefore, this means that when compliance levels are high adolescent experience a better quality of life.

Table 5: Summary statistics results of correlation coefficient test between Compliance levels and quality of life

		Total Quality of Life	Total compliance
Total Quality of Life	Pearson Correlation	1	.468
	Sig. (2-tailed)		.002
	N	40	40
Total compliance	Pearson Correlation	.468	1
	Sig. (2-tailed)	.002	
	N	40	40
**. Correlation is significant at the 0.01 level (2-tailed).			

DISCUSSION

Compliance to treatment

These results suggest that the intervention group showed more compliance to diabetes treatment compared to the control group at follow up. Meaning that adolescent's compliance levels were higher in the follow-up group compared to the control group. The study has reflected that there was a positive impact of information giving intervention in the follow-up group. The information that the adolescents received during the intervention period seemed to have had impacted positively in the lives of the adolescents and also influenced positive behaviour change to the treatment regimen prescribed to them by the doctors.

On the contrally, previous studies indicate that knowledge on compliance is not sufficient for adolescents high levels of compliance, there are behavioural factors which have been found to predict lower compliance rates which include high levels of family stress, poor social coping and problem solving, and inappropriate levels of child responsibility in diabetes management (Parton, 2006).

The factors to compliance that included; times at which insulin was taken, units of insulin change, delay in meal timings, lapses in diet, physical exercises, and hypolyceamic episodes were also explored. The intervention group was able to comply in line with the above factors to compliance compared to the control

group. Knowledge on compliance helps reduce the higher levels of maladaptive coping associated with compliance problems such as anxiety, depression and eating disorders that bring about worse diabetic management in adolescents (Delamater, 2006).

Furthermore, literature indicates that compliance also help patients to take control of their situations with focus on maintaining emotional and physical health. Noncompliance with diabetes treatment regime can lead to life threatening complications (Novato and Gross, 2009). In this study high compliance level was explained on good motivation, a strong sense of normality, energy and will power, support from parents , physicians and nurses, a positive attitude towards the disease and its treatment with no threat to one's social wellbeing and fears of complications (Kyangas, 2000).

Impact of diabetes

The results for impact of diabetes indicated that. The intervention group at follow up had less impact of diabetes compared to the control group at baseline. These results suggest that the adolescents in the intervention group experienced less impact of diabetes at follow up compared to the control group at baseline. The results also indicate that despite adolescents having diabetes they seem to be able to adjust and live positively with the illness. This indicates a positive effect of compliance on the quality of life of adolescents

Worries about diabetes

The effect of compliance on quality of life was further explored with Worries about diabetes. The Results indicated that the intervention group at follow up showed less worries about diabetes compared to the control group at baseline. This means that adolescents in the intervention group at follow up experienced less worries about diabetes compared to the adolescents in the control group at baseline. Therefore there was a positive impact of information given to the adolescents during intervention at follow up. This means that adolescents' negative perceptions about diabetes might have been changed at follow up and the information which adolescents received might have reassured them that diabetes is one of the illnesses that one has to live with this might have made them accept the illness thereby reducing

their worries about diabetes. Furthermore, the adolescents in the intervention group experienced less worries because they were able to interact with each other during the intervention period. They also seemed to have shared their experiences on how to cope with diabetes, social interaction with the parents and family and the positive perception about diabetes. They also seemed to support each other in times of need since they become close to each other.

Although contrally to the findings literature indicate that adolescents may struggle to in-corporate a medical condition into their evolving sense of self associated with psychological consequences such as worries about the illness, depression, stress and eating disorders (Frank, 2007). This may appear to psychologists as denial of the illness and failure to recognize the seriousness of the illness. This may lead to low compliance with diabetic treatment recommendations that include diet, exercise, insulin administration and Hypoglycaemic control (Taddeo, 2008). Therefore, less psychological consequences such as worries would help adolescents with diabetes mellitus type 1 manage their diabetes and reduce negative consequences.

Diabetes can affect an adolescent's emotions both directly and indirectly. Poorly controlled blood sugar can directly affect the emotions by causing behaviour changes, such as bad temper. Adolescents with diabetes have an increased risk of depression and worries. To reduce these psychological effects diabetes specialists should be included such as a social worker or psychologist as part of a diabetes care team. The intervention period had a positive impact on the adolescents in the intervention group because it helped reduce their worries about diabetes thereby improving their quality of life. Furthermore, such interventions must be considered very important in other health centers in Zambia.

Satisfaction with life

Furthermore, satisfaction with life was explored. The Results showed that; the intervention group showed less satisfaction with life compared to the control group at follow up. Such outcome of results could have been due to the behavioural factors which have been found to predict less satisfaction with life that include high levels

of family stress, poor social coping and inappropriate levels of responsibility in diabetes management (Taddeo, 2008). Adolescents are still under the care of parents or significant caregivers in the families who are involved in the care. These people have to remind and encourage the adolescents to take their medications and control their diet according to medical prescriptions. Therefore, negative parental behaviour towards the adolescents may lead to less satisfaction with life among adolescents.

However, previous research postulates that time spent with the family and peers can influence positive attitudes and behaviour that would influence positive effects on adolescents self management that would promote more satisfaction with life (Grayson, 2002).

Further literature postulates that moving toward independence from their parents, adolescents typically want to make their own choices and have a sense of control over their lives. Having a disease may make them feel powerless and they try to gain control by not taking medications, missing appointments or not following dietary restrictions (Health information, 2012). Adolescents may also have a harder time telling friends or boyfriends or girlfriends that they have diabetes because they want to fit in. This may lead to poor compliance that may lead to less satisfaction with treatment (Kent et.,al 2010).

Adolescents with diabetes tend to ignore their vulnerability to potential consequences of their disease in their age appropriate preoccupation with the present (Guthrie, 2003). Such care programmes should be continued in the health centers with the help of qualified psychologists who would help adolescents through counselling that will enhance them appreciate their lives while living with the diabetes condition. This will help adolescents lead a positive life that would promote satisfaction with life leading to better quality of life.

According to findings the demographic results indicate a lot of similarities in the sample between the two age groups (control and intervention groups).

CONCLUSION

It is clear to conclude that there was a relationship between compliance and quality of life among

adolescents with diabetes mellitus type 1. Compliance levels were high in the intervention group with regard to compliance with treatment, impact of diabetes worries about diabetes at follow-up compared to the control group, although there was less satisfaction with life in the intervention group at follow-up.

The adolescents compliance to treatment, impact about diabetes and worries about diabetes were highly significant at follow up compared to the control group and that the information that the adolescents received during the intervention period seemed to have had impacted positively in the lives of the adolescents and also influenced positive behaviour change to the treatment regime prescribed to them by the doctors. The hypothesis that there was a positive correlation between compliance and quality of life was accepted when the bivariate correlation coefficient test was done at a significant level of 0.01. This is in line with literature that indicates that, adolescents often learn to be more compliant in medication usage, diet and exercise programmes and compliance helps the diabetes patients understand fully the degree to which their non-compliance to diet medication and exercise impact their long term health (Cadena, 2007). Therefore, compliance is the number one factor that determines a healthy outcome in the diabetic patient. Compliance also helps patients to take control of their situations with focus on maintaining emotional and physical health. Noncompliance with diabetes treatment regime can lead to life threatening complications (Novato and Gross, 2009).

LIMITATIONS

Data was derived exclusively from self-reports which can contribute bias related to defensiveness of participants. The study characterizes a group of people who are more at risk of poor compliance hence factors such as parental neglect might interfere with their treatment regime though compliance levels improved after intervention in the follow up.

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