

Mothers' perception of stress involved in parenting a diabetic child

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ABSTRACT

Objective: This study investigated mother's perception of stress involved in parenting a diabetic child. **Methods:** Guided by a descriptive study, a target population which consisted of Maltese mothers with children having insulin-dependent diabetes that attended the out-patient diabetes clinic in St. Luke's Hospital was surveyed. Well structured self-administered questionnaires were used in collecting data. Parental stress index (PSI) subscales vis-à-vis parental distress (PD), parent-child dysfunctional interaction (P-CDI) and difficult child (DC) were the yardsticks that were used to measure mother's perception of stress involved in parenting a diabetic child. Generated data were subjected to descriptive statistics and correlation and regression analysis with regression line charts. **Results:** Results showed that mothers who had diabetic children were highly stressed with 19 out of 25 mothers scoring over 85th percentile in the parental stress index. It was also found that PSI subscales had the following trend in increasing order of stress on the mothers; P-CDI < DC < PD. This implied that PD had the greatest impact followed by DC and lastly P-CDI. **Conclusion:** It was therefore surmised that mothers with diabetic children perceive and experience a lot of stress as a result of having a diabetic child. Hence, it was recommended that further study should be carried out on father's perception of stress involved in parenting a diabetic child.

Key words: Diabetic Child, Perception of Stress, diabetes mellitus, Parenting, Maltese Mothers

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INTRODUCTION

Diabetes Mellitus is a major health problem in Malta, a feature shared with several other island communities.¹ Diabetes mellitus affects from 1 to 2 of every 1000 children younger than 18 years of age.^{2,3} It is the most common endocrine disease of childhood, occurring most commonly during the school-age period.⁴ As members of the family unit, children with chronic conditions such as diabetes, influence family behaviour socially, emotionally, physically and financially.⁵

There are 145 children between the ages of 1 to 18 years who are diabetic.⁶ There were 60 admissions of children between the ages of 6 years to 13 years to St. Luke's

Hospital which is the main hospital in Malta between 1994 and 1998 as a result of diabetes and its complications.⁶ Therefore, diabetes complications are laying heavy costs on the health services while causing the children irreversible damage to their quality of life and adding frustrations to their mothers in managing their condition. Studies on parental stress associated with diabetes has tended to focus on mothers, because they typically bear the responsibility for co-ordinating the day-to-day management of their child's disease.⁷

The term "perception of stress" refers to the difficulties; problems and hassles mothers pass through during the upbringing of their diabetic child or children. A quantitative study was carried out in the University of Virginia⁷ on the

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level of stress experienced in the parenting role by mothers of 49 children with insulin-dependent diabetes mellitus, and its relationship to glycemic control. This study used the parenting stress index (PSI) to examine mothers' stress and analysis of the results showed that mothers with diabetic children are more stressed; less attached to their children, are prone to poorer health and have more demanding children. It has been observed that mothers of diabetic children often exhibit resentment, rejection, and a decrease in self-esteem.^{8,9} Consequently, this study, using a survey design sought to explore the level of stress in mothers with diabetic children and mother's perception of stress as a result of having a diabetic child in Malta.

MATERIALS AND METHODS

Research Design

In this descriptive study, a survey design was used. Descriptive studies seek to gain more information about characteristics within a particular field of study,¹⁰ which in this case is a sample of Maltese mothers of insulin-dependent diabetic children. This research design was considered to be appropriate since the study was intended to "describe and explore the subjects rather than examine cause-effect relationships".¹¹

Target Population and Sampling Technique

The target population consisted of Maltese mothers whose children had insulin dependent diabetes and were attending the out patient diabetes clinic in St. Luke's Hospital (SLH). In this study the accessible population, that is, the portion of the target population to which the study has reasonable access,¹⁰ excludes all mothers of insulin-dependent diabetic who do not attend this clinic.

The sampling method used for this study was convenient sampling, whose subjects were included because they happened to be in the right place at the right time,¹⁰ with a proposed choice was 40 mothers. However, some of them did not meet up with the inclusion criteria. It has been suggested¹¹ that a response rate "greater than 60% is probably sufficient for most purposes" in view of the population of 40 diabetic children between 6 to 13 years at the Diabetic Clinic, SLH. Therefore, the respondents are representative, relative to the target population. Sample size was obtained by searching the patients' medical files and computer at the Diabetic Clinic, St. Luke's Hospital.

Research Instrument

Well structured/tailored self-administered questionnaires were used. The tool was translated into the Maltese language. Parents also completed a demographic data sheet on family composition including child's age at diagnosis,

educational level, occupation of parents, ages of parents and siblings living in the home, support group participation.

The Parenting Stress Index

The Parenting Stress Index (PSI) is based on a framework of stressful issues encountered by mothers who are parenting children with chronic disease such as diabetes. The Parenting Stress Index (PSI) was developed by¹² and other professional like paediatricians and child psychologist in America. This was conceived 25 years ago and had undergone a series of revisions.¹² The PSI is suggested for use by clinicians and researchers who work with parents and children in a variety of settings. Thus, the PSI contains 36 items divided into two domains reflecting characteristics of the mother and child associated with stress.¹² Each item is scored on a 5-point scale, with high scores indicating stress in some aspect of the mother-child relationship. The child domain represents characteristics of the child that tend to be particularly stressful to the parent and may be associated with behavioural or other development problems.^{13,14} This domain also yield five scores including poor child adaptability to new situation, possession of characteristics perceived as unacceptable by the mother, depressed mood, excessively demanding behaviour in the child and excessive distractibility. The scores from this domain are added together to yield an overall stress score for the child.

The parent domain represents characteristics of the parent or the parent's environment that contribute to greater parental perception of stress. This domain yields seven scores, including maternal depression, poor maternal attachment to the diabetic child, perceived maternal incompetence as a parent, perception of being restricted by the parenting role, a sense of social isolation and poor maternal health.

Validity and Reliability Issues

Parental stress index is a standard tool according to Hauenstein et al⁷ who pointed out that acceptable levels of internal consistency (Cronback's α) have been demonstrated for the overall stress score (.95), the scores for both the parent and child domains (.93 and .89) respectively; and to a lesser degree, many of the subscale scores (55-80, median .66). Test-retest reliability, construct validity and predictive validity have been demonstrated for this instrument.¹⁵⁻¹⁷ A pilot work gave a positive indication that the instrument measured what it was intended to measure.

Pilot Works and Modifications

Prior to the use of the questionnaire in this study, pilot testing was done to determine clarity of questions on the questionnaire guides. It was conducted with four mothers who met the inclusion criteria. Although, the tool was

developed in the United States, a pilot study checked if the tool fitted into the Maltese situation and also because of the translation of the PSI into Maltese language to check if the tool was understood well. The questionnaire ideally, takes 10–15 minutes to fill depending on the individual mother's understanding under normal circumstances.¹² However, more time was taken by these mothers in filling the questionnaire like up to 30 to 40 minutes.

Ethical Considerations

Approval for the study was obtained from the consultant of the diabetic clinic, St. Luke's Hospital. Mothers of diabetic children received an explanatory letter of what the study was all about. The study made sure that the data provided by subjects were not used in any way that could adversely affect them as individuals or as members of any group of which they were part of.

Procedure

Names, addresses and telephone numbers of prospective subjects who met the inclusion criteria were obtained from clinic rosters at the diabetic clinic, St. Luke's Hospital. Families received consent letter from the investigator describing the study, assuring confidentiality and requesting for participation. An appointment at the convenience of the mothers was arranged either at the diabetic clinic or in the subjects' home. After receipt of consent from the mothers, the parenting stress index questionnaire was administered. The problem of language barrier was tackled by employing a translator who was present all the time of administering the questionnaire to the mothers to facilitate understanding. Ideally, the filling of the questionnaire was supposed to last for 10-15 minutes,¹² but these mothers spent up to 30 to 40 minutes time range in filling their questionnaires.

Scoring

The following is a guide to how the responses were scored according to Abidin.¹² The shaded items in the questionnaire were (1, 2, 3, 7, 8, 9, and 11) and these items were summed up to correspond to the Defensive Responding. The defensive responding is not included in the subscales.¹² These are three subscales namely, Parental Distress (PD), Parent-Child Dysfunctional Interaction (P-CDI) and Difficult Child (DC) subscales. They contain 36 questions in the Parenting Stress Index (PSI) questionnaire. Each subscale had 12 questions in it.

In parental distress subscale, sum items 1 through 12 to obtain the raw score of parental distress. This is done by calculating the respondents' cycled items on the PSI test sheet such as SA (strongly agree), A (agree), NS (not sure), D (disagree), or SD (strongly disagree). These correspond to a range of scores from 5 to 1 in this

order with SA having the highest score and SD having the lowest score.

Assuming the raw score obtained from 1 to 2 which is the parental distress subscale is 33, using the "scoring sheet", the raw score of 33 corresponds to 85th percentile. In the same manner, assuming 27 is obtained from parent-child dysfunctional interaction (P-CDI) as a raw score, its corresponding value in the scoring sheet will be 90th percentile. And items 25 through 36 correspond to difficult child subscale. If 41 were obtained as raw score for difficult child, its corresponding value in percentile will be 96th percentile. However, to obtain the total stress, sum the scores for parental distress, parent-child dysfunctional interaction and difficult child subscales. This would give the overall scores stress of an individual mother. It is important to note that family codes which are not mentioned here 005, 014, 025 and 029 were used for pilot work.

Data Presentation and Statistical Analysis

Generated data were presented in Tables. Obtained data were subsequently subjected to descriptive statistics, correlation and regression analysis in which case coefficient of simple determinants, r^2 , were obtained in order to find out how each of the parental stress index subscales (PD, P-CDI and DC) contributed to total stress on the mothers; this was enhanced by the plotting of regression lines for each of the PSI subscales against total stress.

RESULTS AND DISCUSSION

Parental Stress Index (PSI)

Defensive Responding

The Defensive Responding scale assesses the extent to which the respondent approaches the questionnaire with a strong bias to present the most favourable impression of her and to minimize indications of problems or stress in the parent-child relationship. Castaldi,¹⁸ and Lafiosca and Lloyd¹⁹ called it validity indicator. That is to say that extremely low score, like a raw score of 10 or below will introduce biases into the result. Therefore, in Table 1, in the defensive responding, none of the scores of the mothers was below or at 10 raw score rather, it ranged from 13 to 31 which implies that the mothers filled the questionnaire with honesty and as it affected them.

Parental Distress

Parental Distress (PD) subscale determines the distress a parent is experiencing as a result of personal factors related to parenting.^{14,20} The component stresses associated with the parental distress (PD) subscale are impaired sense of parenting competence, stresses associated with the child's other parent, lack of social support, and presence of depression, which is a known correlate of dysfunctional parenting. When the parental distress (PD) subscale is

Table 1: Parental stress index raw scores and their respective percentile

Code of families	Defensive responding	Parental distress	Parent-child dysfunctional interaction	Difficult child	Parental stress	Percentile
1	25	46	26	26	98	94
2	27	48	29	49	126	>99
3	22	30	41	41	112	99
4	24	37	27	39	103	96
6	22	32	22	32	86	85
7	22	35	12	22	69	50
8	26	37	21	45	103	96
9	22	33	14	17	64	32
10	31	43	27	42	112	99
11	23	33	33	48	114	>99
12	22	32	24	35	91	90
13	30	47	28	22	97	94
15	22	33	14	38	85	84
16	25	39	36	31	106	97.5
17	21	32	24	36	92	92
18	22	35	26	36	97	94
19	17	30	28	34	92	90
20	20	31	12	31	74	62
21	30	50	17	30	97	94
22	27	39	29	33	101	95.5
23	31	51	15	38	104	96.5
24	31	48	50	53	151	>99
26	13	19	31	37	97	87
27	25	40	16	29	85	84
28	18	30	15	24	69	50

the highest elevation among the three subscales, it is recommended that further exploration of the parent's personal adjustment be conducted.¹² However, Abidin¹² considers scores at or above 85th percentile as high scores, and high scores suggest that mothers are highly stressed.

As shown in Table 1 in the parental distress subscale, 17 out of 25 mothers had scores at or above 85th percentile which implies that these mothers have stresses which are independent of the child. However, the parental distress on its own could not be the determinant factor of the mothers' stress. Scores from the parent-child dysfunctional interaction (P-CDI) and difficult child (DC) would help to evaluate mothers' stress. Conversely, Abidin¹² suggests that when a parent earns a parental distress score above the 90th percentile and difficult child (DC) subscale score below the 75th percentile then, it is likely that the parent is experiencing personal adjustment problems that are at least partially independent of the parent-child relationship. In these families (001, 013, 021 and 027) these mothers scored more than 90th percentile in the parental distress with scores at or less than 75 percentiles in the difficult child subscale. This implies that these mothers were experiencing stress from other life roles, independent of their children.

Parent-Child Dysfunctional Interaction

The Parental-child Dysfunctional Interaction (P-CDI) subscale focuses on the parent's perception that her child does not meet the parent's expectation, and the interactions with her child are not reinforcing to her as a parent. The

parent projects the feeling that her child is a negative element in the parent's life.¹² Commonly, the mother's description of the parent-child relationship suggests that the parent either sees herself as abused by, or rejected by the child, or she is disappointed and feels alienated from the child. In Table 1, that is the subscale of parent-child dysfunctional interaction, approximately half the mothers scored at or above 85th percentile which suggests that the parent-child bonding is either threatened or has not been adequately established.¹² As such, the mothers experience stress as a result of parenting these children. Again, Abidin¹² points out that if both the parent-child dysfunctional interaction (P-CDI) and difficult child (DC) subscale scores are above the 90th percentile and the parental distress subscale score is at or below the 75th percentile, it is likely that the parent is coping with exceptionally difficult behaviour or personality characteristics of her child. Families with code 003 and 026 met these criteria, which show that the stress which is emanating from the children is high; the subscale of parental distress is normal which indicate that the mothers were coping with this stress.

Difficult Child

The Difficult Child (DC) subscale focuses on some of the basic behavioural characteristics of children that make them either easy or difficult to manage. These characteristics are often rooted in the temperament of the child, but they also include learned patterns of defiant, non-compliant, and demanding behaviour.²¹ In Table 1, 15 mothers out of 25 scored more than 85th percentile which is considered high scores. High scores in this subscale (DC) indicate

Table 2: Pearson correlation matrix of parental stress index

	TS	DC	P-CDI	PD
TS	1.00	0.823***	0.827***	0.466**
DC	0.823***	1.00	0.584**	0.122 ^{NS}
P-CDI	0.827***	0.584**	1.00	0.081 ^{NS}
PD	0.466**	0.122 ^{NS}	0.081 ^{NS}	1.00

P-CDI: Parent-child dysfunctional interaction, DC: Difficult child, TS: Total stress, ***: Very highly significant at $P < 0.001$, **: Highly significant at $P = 0.002$, *: Significant at $P = 0.019$, NS: Not significant at $P = 0.562$ (PD against DC), Not significant at $P = 0.701$ (PD against P-CDI)
Source: Abidin R. R. Parenting Stress Index, 2000. 3rd Edition (PSI)

that these mothers are stressed as a result of parenting their diabetic children. As these researchers pointed out that high scores produced by parents of these children are related to measures of child-behavioural adjustment and to behavioural symptoms.¹⁴ They suggested that in these families, the parents are typically experiencing difficulty in managing the child's behaviour in terms of setting limits and gaining the child's co-operation. In this study six mothers (with family codes 002, 003, 008, 010, 011 and 024) scored more than 95th percentile, which could suggest that these mothers are highly stressed.

Total Stress

The Total Stress score is designed to provide an indication of the overall level of parenting stress an individual is experiencing.¹² A parent's total stress score reflects the stresses in the areas of personal parental distress; stresses derived from the parent's interaction with the child, and stress that result from the child's behavioural characteristics.

Table 1, shows the summation of the raw scores from the three subscales which resulted to the total stress. In Table 1, the total stress raw scores ranged between 91 and 151 with the mother who scored 151 being the most stressed. From the same Table, the result shows that 17 out of 25 mothers scored more than 90 on their raw scores. Abidin¹² contends that mothers who had these scores are experiencing clinically significant levels of stress. Overall it could be argued that more than half of the mothers who participated on this study could be suffering from stress as a result of parenting their diabetic children.

Mothers' Perception of Stress as a Result of Having a Diabetic Child

In Table 1, 19 mothers out of 25 had scores at or above the 85th percentile on total stress which is considered a high score.¹² These high scores are perceived in reality by these mothers that they were not finding parenting easy to manage their diabetic children. As a consequence, these mothers with high scores were having a negative impact as a result of their diabetic children's behaviour while the remaining mothers could be considered as having positive adjustment

because their children could not be causing them a lot of stress as indicated in the normal scores. The current finding supports the previous findings of Kazak et al⁵ who claimed that positive outcomes as well as negative outcomes had been reported by parents with diabetic children.

The planning of programmes for the diabetic children by their mothers has been perceived to be stressful. These programmes could include regular insulin injection, meal planning, urine testing and blood monitoring,²² watching the child play (Krauser and Madden²³) co-ordinating the diabetic child's siblings and above all, the financial impact (Hodges & Parkers²⁴) where the money is not available. All these factors could be perceived as possible stressors to these mothers of diabetic children.

A significant proportion of mothers in the study perceived that their diabetic children have numerous psychological difficulties and experience personal stress associated with their role as parents as indicated in the subscales. It is important for mothers to acknowledge that their child's diabetes may cause them to view their child more negatively than their healthy siblings and that they may need help in identifying their child's positive qualities.

In view of the per cent mean (Table 1) of various PSI subscales –PD, P-CDI and DC on total stress, and the coefficient of simple determinant, r^2 (Figure 1a-c), it can be surmised that mother's perception of stress in parenting a diabetic child as influenced by PD, P-CDI and DC had the following trend in increasing order of stress on the mother $P-CDI < DC < PD$. This implies that PD had the greatest impact followed by DC and lastly P-CDI.

Limitations of the Study

There are some factors that limit the ability to generalize the findings in this study. Children with diabetes in this study were treated in a diabetic clinic center; St. Luke's Hospital and may be different from those seen in a community setting, or private clinics. The findings are not generalisable therefore to the whole population of mothers of diabetic children living in Malta.

Another possible limitation is that the tool (PSI), which has been devised for an American setting, has been used with Maltese mothers. To encourage participation the toll was translated from English to Maltese language, however, it is possible that some Maltese mothers may have found the content strange given their cultural background. In view of this, it could be suggested that this could possibly affect the response of these mothers.

Another limitation is the use of parent reports of child behaviour. Hubert et al²⁵ assert that such reports may have

limited validity. Also the stress levels reported by parents may be temporary or may not specifically relate to their child's diabetes.

CONCLUSION

In spite of the limitations, the findings do give insight into the mothers' perception of stress involved in parenting a diabetic child. The major findings were that mothers of diabetic children experience a lot of stress as a result of having a diabetic child.

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Authors Contribution:

NJC – Concept and design, acquisition of data, analysis and interpretation of data, Manuscript preparation, Critical review and approval of manuscript; **SIND** – Concept and design, acquisition of data, analysis and interpretation of data; **NAA** – Concept and design, acquisition of data, analysis and interpretation of data; **COE** – Concept and design, acquisition of data, analysis and interpretation of data; **SNOI** – Concept and design, acquisition of data, analysis and interpretation of data; **JT** – Concept and design, acquisition of data, analysis and interpretation of data.

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