Bouncing forward: families living with a type I diabetic child

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Abstract

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Background: Despite the multitude of challenges that families living with a child with diabetes face, they have been found to adapt to such an extent that diabetes is viewed as a manageable condition. This study was concerned with the factors that enable these families to adapt. The internationally acclaimed Resiliency Model of Stress, Adjustment and Adaptation served as the framework to conceptualise the families' adjustment and adaptation processes.

Methods: The study was triangular in nature, with an exploratory, descriptive approach; non-probability purposive and snowball sampling techniques were employed. Sixteen families participated in the research. A biographical questionnaire, which included an open-ended question, to be completed in written format, was used in conjunction with seven structured questionnaires to gather relevant data. These seven structured questionnaires were an operationalisation of some of the key concepts and processes of the Resiliency Model. Descriptive statistics were used to describe the biographical information. Quantitative data were analysed by means of correlation analysis, while qualitative data were analysed by means of content analysis.

Results: Various resilience factors were highlighted, including family time and routines, communication, hardiness, the acceptance of the diabetes, adherence to a treatment regimen, the obtaining of knowledge and skills, and working together as a family unit in managing the diabetes.

Conclusions: Family plays a powerful role both in the treatment of chronic illness and in paediatric practice. This article highlights the central role of family in the management of type I diabetes and provides practitioners with insight into the challenges that families face, as well as the strengths that can be developed to improve their resilience in relation to this chronic illness. The identified variables are valuable, in that they can be used as a map to guide prevention and intervention efforts in helping families live with type I diabetes.

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Introduction

The impact of a chronic illness on a diagnosed individual can be significant, as a chronic illness is degenerative and pervasive in nature.[1] Diabetes mellitus, a chronic illness, is one of the unique stressors that families face in the 21st century. Families play central roles in the care of children with chronic illness, as seen in the relationship between family functioning and the metabolic control of type 1 diabetes.[2] Research and practice in family psychiatry show that families have powerful influences on health and chronic illness that are equal to and, in some cases, surpass other risk factors.[3]

A family's initial reaction to the diagnosis of type I diabetes is often compared to that of the grieving process.[4] In addition to the new challenges of care that families have to face, they also have to adapt to the crisis quite rapidly, as people living with diabetes are at increased risk of developing medical and psychosocial complications.[5,6] Medical complications can include blindness, cardiac disease, end-stage renal failure and non-injury-related lower limb amputation.[7] To manage the diabetes successfully, family members have to become involved in the treatment regimen, which entails insulin injections, the monitoring of blood glucose levels with glucose-monitoring systems, the management of meals and the implementation of exercise programmes.[6] It is important that the entire family unit is involved in a child's type 1 diabetes management,[8] as this can significantly enhance adherence and metabolic control.[9]

The psychosocial impact of diabetes on a family's functioning can be pervasive,[10] psychosocial stressors and challenges being as significant in diabetes control as the physical and medical complications associated with diabetes itself. The successful management of diabetes includes the effective management of stress, as stress can destabilise blood

sugar levels and, therefore, negatively impact metabolic control in type I diabetes.[11] Psychosocial challenges can include delays in the completion of developmental tasks,[5] the infantilisation of the diabetic child,[10] the diabetic child experiencing emotions such as denial, fear, anxiety, anger, guilt and depression,[12] and possible stigmatisation by day-care workers, teachers and peers.[13] The parental subsystem is also exposed to psychosocial challenges, such as grief, anxiety and a depressed mood from persistent hypervigilance regarding the health of the diabetic child.[7] Mothers are at risk of depression due to loss related to child bonding, marital cohesiveness and sources of support, who may withdraw due to fear.[13] The sibling subsystem also experiences the effects of diagnosis, as siblings often assist with the care of a diabetic child[10] and may experience feelings of inequality regarding the amount of attention received from the parents.[14]

Despite these challenges, however, families are able to utilise their strengths and bounce back from adversity[15] by using protective factors, such as parental mutuality,[14] problem-solving skills,[16] the expression of emotions,[17] the development of an instrumental support system[13] and spirituality and religion.[18,19] This ability of families to bounce back is referred to as family resilience, which is a construct that highlights humanity's ability to bounce back from adversity.[20] This definition affirms the reparative potential of families and acknowledges that families effectively work through and learn from adversity by integrating their crises into the life history of the families.[21]

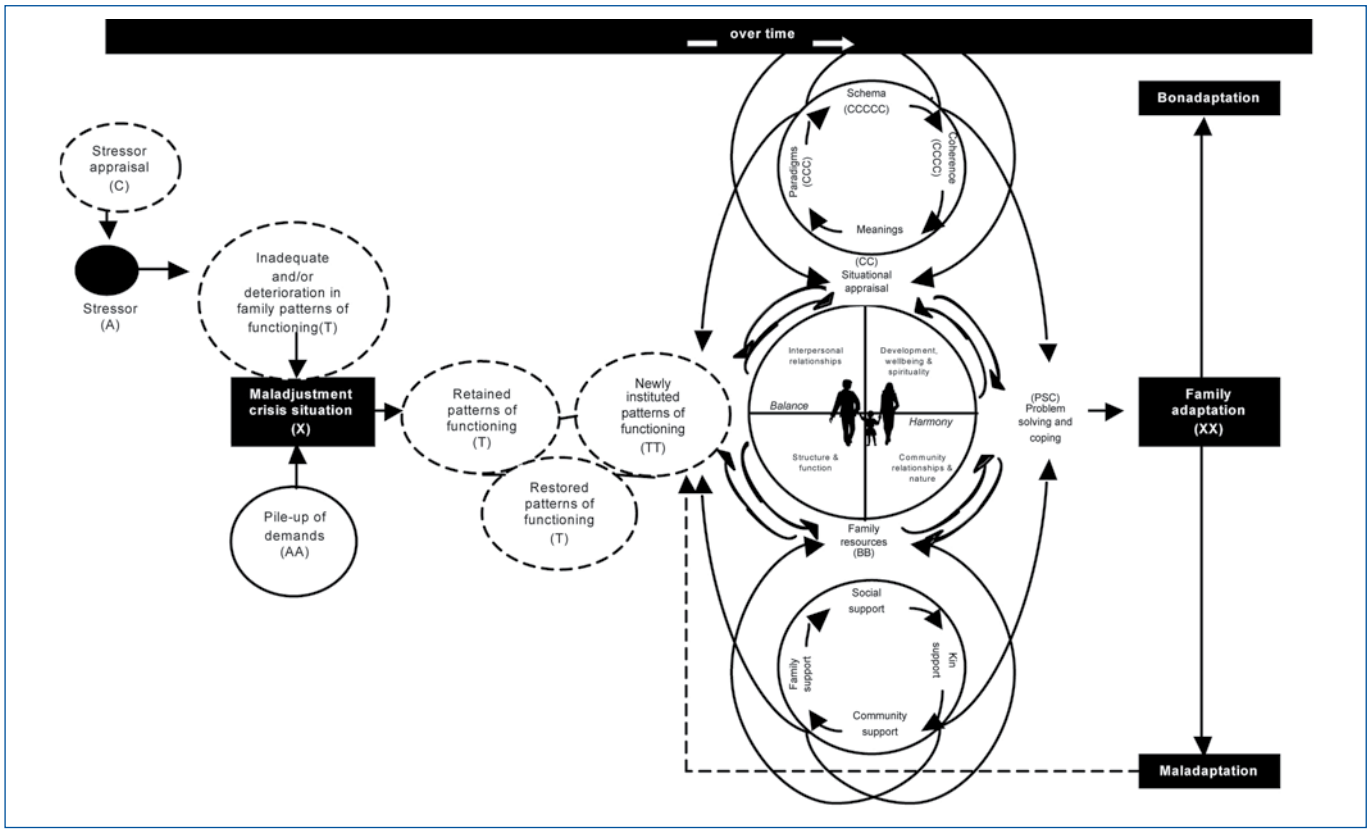
A family-resilience framework is valuable in a research and intervention context, as it can be applied to a wide range of crises and persistent life challenges.[22] Some of the advantages of using such a framework include the fact that it focuses on strengths under stress, assesses functioning in context and does not assume that a single model fits all families. In addition, the framework recognises the optimal functioning and well-being of family members to vary over time depending on challenges arising and the life cycle of the family.[23] Using a family-resilience framework in an intervention context could, therefore, lead to reduction in dysfunction and enhance family functioning and individual well-being.

Theoretical framework

The Resiliency Model of Family Stress, Adjustment and Adaptation (the Resiliency Model) involves two distinguishable but related processes, namely adjustment and adaptation.[24] The second process, adaptation (Figure 1), involves the influence of recovery factors in promoting a family's ability to bounce back and adapt in family crisis situations. This was, therefore, the focus of this study.

When a family crisis is experienced, the family enters the adaptation phase of the Resiliency Model.[24] Family crisis can be defined as "a state of imbalance, disharmony and disorganization in the family system".[25] Pile-up of demands (AA) refers to the accumulative nature of pre- and post-crisis stressors.

Figure 1: Adaptation phase of the Resiliency Model of Family Stress, Adjustment and Adaptation[24]



A family has patterns of functioning that determine the operational processes of the family. During a crisis, these patterns often have to be adapted or discarded depending on the nature of the crisis. Retained and restored patterns of functioning (T) and newly instituted patterns of functioning (TT) interact with a family's appraisal processes, resources (BB: social, family, kin and community support) and problem-solving and coping (PSC) abilities to produce the outcome of family adaptation (XX). A family's appraisal processes in crisis situations consist of five levels, namely schema (CCCCC), coherence (CCCC), paradigms (CCC), situational appraisal (CC) and stressor appraisal (C).[25]

As mentioned, the outcome of the adaptation phase of the model is family adaptation (XX). Adaptation can be either positive or negative. Bonadaptation implies that a family is able to stabilise, promote the individual development of its members and achieve a sense of congruence, despite being faced with major changes in the patterns of family functioning. Maladaptation refers to unsuccessful adaptation, where a family sacrifices personal growth and development and the family's overall sense of well-being, trust and sense of order becomes very low.[25] This study does not aim to measure the level of adaptation in terms of bonadaptation or maladaptation, but rather to identify the factors that are correlated with bonadaptation.

Research design and methodology

The triangulation of method with an exploratory, descriptive approach was used. A combination of non-probability purposive and snowball sampling was used to obtain the sample. The study settled on two inclusion criteria, namely (a) that participating families had to include a child between the ages of four and twelve years who had been diagnosed with type I diabetes for a minimum of six months and (b) that research participants had to have Grade 8 proficiency in either English or Afrikaans. A specific age range was chosen to homogenise the life-cycle stage of the families. The reason for this age range is that children younger than four cannot take responsibility for the management of chronic illness and a family is, therefore, most actively involved in the management of the diabetes from birth to preadolescence, since independent care is encouraged during adolescence. Subsequent to obtaining permission to conduct the study from the Ethics Committee (Human) of the Nelson Mandela Metropolitan University, DiabetesSA and the Chief Medical Officer at a state hospital in the Nelson Mandela Metropolitan Municipality were contacted to gain access to possible sampling resources, such as the family diabetes support group and the endocrine clinic. Families were informed of the purpose and value of the study, and their right to confidentiality and anonymity, as well as their right to withdraw from the study at any time.

A biographical questionnaire was used to obtain demographic information and included an open-ended question based on the Resiliency Model. The questions aimed to uncover the factors or strengths that the participating families believed helped them through their crisis. The questionnaire was completed in written form. In addition, seven structured paper-and-pencil measures were used: the Relative and Friend Support (RFS), the Social Support Index (SSI), the Family Crisis-Oriented Personal Evaluation Scales (F-COPES), the Family Hardiness Index (FHI), the Family Time and Routine Index (FTRI), the Family Problem Solving Communication (FPSC) and the Family Attachment and Changeability Index 8 (FACI8, the dependent variable). All the measures used had adequate reliability and validity indices; Cronbach alphas for the sample were also calculated and found to be appropriate. Two caregivers per family completed separate sets of the questionnaire.

Tesch's model of content analysis was used to analyse the qualitative data. Guba's model of trustworthiness was used to account for the researcher's bias and subjectivity. Pearson product-moment correlations (Pearson *r*) were used to manipulate the quantitative data and Guilford's guidelines were used to interpret the magnitude of the relationship between variables.

Results and discussion

Sample description

A total of 16 South African families (31 participants) participated in this study, 17 of the participants being female and 14 being male. The majority of the participants were English speaking (N = 16). The time lapse since the diabetes diagnosis ranged from 12 months to 96 months (i.e. 8 years); research has indicated that the adaptation process takes approximately one year.[4]

Qualitative findings

Various themes emerged from the verbatim responses of the research participants. These are discussed in the order of frequency with which they occurred.

Literature has reflected the importance of social support as a mediator of personal well-being and bonadaptation for families living with type I diabetes.[14] Examples of how the participants communicated the importance of social support included the following:

> *Oumas en Oupas bied baie emosionele ondersteuning.* [Grandmothers and grandfathers offer a lot of emotional support.] (i.e. emotional support)
>
> My friends are all mature and help a lot. (i.e. social support)

While social support has been demonstrated as a significant resilience resource, the families reported that it was difficult to entrust the care of their child to family members and friends who may not be knowledgeable about type I diabetes.[26]

Literature has also suggested an important link between

spirituality or religion and coping with and adapting to chronic illness.[19] Some crises in family life cycles cannot be explained by reasoning and logic alone and families that struggle to find meaning when a young child is diagnosed with a chronic illness may find this meaning through their spiritual beliefs and practices.[22] Religion provides families with an interpretative framework and cognitive schema, which, in turn, provides a sense of predictability, control and self-worth. A sense of control can also be derived from religious beliefs and practices, such as prayer, and has been associated with greater psychological adaptation. Other religious practices, such as attending church, facilitates access to social support and enhances social integration.[27] Examples of these references included the following:

> *Geloof en vasberadenheid en hoop op genesing – eendag!* [Faith and determination and hope for healing – one day!]
>
> We had a lot of prayer and that is how we got through the first month.

The effective management of a child's chronic condition requires accurate and adequate knowledge and skills regarding issues such as administering insulin injections, monitoring blood sugar with glucose-monitoring systems and managing meals and physical activity.[4] The participants highlighted the importance of obtaining knowledge and skills related to type I diabetes as follows:

> *Stel belang in leesstof, meer inligting en het lesings bygewoon.* [Show interest in reading material, more information and the attendance of seminars.]
>
> Finding out as much as possible about the condition or disease.

The participants also identified a supportive family unit as essential to their family's adaptation. Some of the participants made the following specific references to the supportive role of the child's siblings:

> Siblings learn to be helpful.

The whole family's involvement is important, as in the following example; literature has reiterated the significance of the support that family members can offer one another:[10]

> Her diabetes is not her problem alone to deal with, but the whole family's.

The participants also emphasised the significance of their child's acceptance of the condition as a contributing resiliency factor. The child's acceptance of the condition is essential, as denial of type I diabetes could lead to serious mismanagement and impair the family's ability to adapt:[28]

> The child's attitude towards her diabetes inspired me to accept the condition and to be there for her.
>
> *Die kind se aanvaarding van haar toestand help baie.* [The child's acceptance of her condition helps a lot.]

Adherence to a strict treatment regimen is key in the management of type I diabetes,[28] often requiring family members simultaneously to become surrogate dieticians, doctors and diabetes educators, as follows:[4]

> *. . . ons hele gesin het ons eet- en oefeninggewoontes aangepas.* [. . . our whole family adapted our eating and exercise habits.]
>
> We worked out a regime in which we stick or adhere to very rigidly.

Incorporating the stringent treatment regimen is a challenging task for a family unit; literature has suggested that it is the mother who usually carries the burden of care.[9] The participants, however, highlighted the importance of parental mutuality in their adaptation as a family unit. Parental mutuality in diabetes management is associated with a family that thrives and that does not view the child's condition as a threat to the family's future happiness or to marital satisfaction;[13] parental mutuality creates a more secure and nurturing family environment for the child, which is then associated with good outcomes in the child's adaptation to type I diabetes.[29] The marital relationship has also been highlighted as a factor that contributes to family adaptation, since a child with a chronic illness may cause strain in the marital relationship at a time when the parents' support of each other is important:[14]

> Working together as a team.
>
> Support and cooperation from my husband.
>
> The marriage must be strong to survive the onslaughts of the extra strain that a special needs child adds.

Researchers have indicated that affirming communication is an important general resiliency factor when navigating through a crisis situation:[25]

> Having a good relationship with my husband where we can solve problems.
>
> Regular discussions on how to best handle problems related to the disease.

In line with the communication factor, the research participants also emphasised truthfulness as a resiliency factor that facilitated their adaptation; literature has similarly highlighted truthfulness as a general resiliency factor.[30] Obtaining truthful information seems to be vital to a family's adaptation processes, especially when the family is compelled to change its patterns of functioning. Truthfulness is also important in the context of medical, social and psychological intervention programmes that inform and support families through such challenges:[5]

The Resiliency Model advocates that financial stability is a resistance resource that facilitates adjustment.[24] The research participants underscored the importance of financial resources, such as a good income and medical aid benefits, in contributing to living with type I diabetes successfully, as follows:

> Medical aid is helpful. Medicine is very expensive.

Being financially OK – having access to cell-phones, cars, good food, etc.

Hope, which refers to the wishes or desires that a family feels confident will be fulfilled, is a vital resiliency factor in the process of adaptation. It is a future-orientated belief that enables the family to see beyond its problem-saturated present and fuels energy and efforts to rise beyond adversity:[30]

Waiting together for the miracle cure.

. . . hoop op genesing – eendag! [. . . hope for healing – one day!]

Quantitative findings

The results of the quantitative analyses are presented in Table I.

Table I: Pearson product-moment correlations between adaptation (FACI8) and potential resilience variables

VARIABLES (N = 31)	R	p
RFS		
Total RFS score	0.219	0.237
SSI		
Total SSI score	0.102	0.585
F-COPES		
Reframing	0.193	0.298
Passive appraisal	-0.009	0.960
Social support	0.304	0.096
Spiritual and religious support	-0.010	0.957
Mobilisation	-0.046	0.807
FHI		
Commitment	0.265	0.149
Challenges	0.534	0.002*
Control	0.234	0.205
Total FHI score	0.537	0.002*
FTRI		
Behaviour total score	0.411	0.022*
Value total score	0.096	0.613
FPSC		
Affirming communication	0.731	0.000*
Incendiary communication	-0.389	0.031*
Total FPSC score	0.620	0.000*
Time period since diagnosis	0.211	0.433

*$p < 0.05$

The results of the quantitative analysis suggested significant correlations with family hardiness (as measured by the FHI), engagement in family time and routines (as measured by the FTRI), communication (as measured by the FPSC) and family adaptation (as measured by the FACI8, which represents the dependent variable). Family hardiness ($r = 0.54$, $p = 0.00$) is concerned with the internal strength and durability of a family unit and refers to a sense of control that the family experiences in terms of the outcomes of life events and hardships,[24] the family making a commitment to work together to resolve crises and to reframe and define hardships as challenges.[30] Adaptation in families living with a type I diabetic child tends to be facilitated through this working together, particularly in the form of parental mutuality. Literature has highlighted parental mutuality and reframing the type I diagnosis as a challenge and as factors associated with adaptation in such families.[13] The significant positive correlation ($r = 0.53$, $p = 0.00$) between the challenge subscale of the FHI and the FACI8 highlighted the participants' ability to be innovative and motivated to experience new things. Literature on type I diabetes has reinforced the fact that parents need to obtain skills and knowledge about the illness to facilitate adaptation.[14] The qualitative findings also highlighted the importance of parental mutuality and the obtaining of knowledge and skills pertaining to the management of type I diabetes.

A significant moderate correlation was found between the behaviour subscale of the FTRI and the FACI8 ($r = 0.41$, $p = 0.02$). The specific activities and routines that a family engages in offer relatively reliable indices of family integration and stability[24] and create a sense of predictability.[30] A diagnosis of type I diabetes could lead to changes in the day-to-day life of all family members.[4] An outcome of bonadaptation requires the adoption of new routines and rituals to incorporate the special requirements of the chronic illness. In addition, these new patterns of functioning need to be integrated with the old routines and rituals of the family.[31]

Furthermore, a significant substantial relationship between FPSC and family adaptation ($r = 0.62$, $p = 0.00$) was found. Literature and the findings of this study have indicated that positive communication facilitates a family's ability to recover from a crisis and that negative communication typically aggravates a situation and adds to the family's level of vulnerability.[21] These results were confirmed by the qualitative findings.

Contributions and recommendations

Family plays a powerful role both in the treatment of chronic illness and in paediatric practice.[3] This article highlights the central role of family in the management of type I diabetes and provides practitioners with insight into the challenges that families face, as well as the strengths that can be developed to improve their resilience in relation to this chronic illness. The identified variables are valuable in that they can be used as a map to guide prevention and intervention efforts[21] in helping families cope with the stress related to type I diabetes. These prevention and intervention efforts are important, since research findings have suggested that stress could have a negative impact on the metabolic control of a child living with diabetes.[13]

Health practitioners also play an important role, which stretches beyond the biological treatment of the illness; families can be encouraged to attend support groups. Families with a spiritual or religious affiliation can be encouraged to draw on this resource as they negotiate

their way through the illness. Health practitioners can, furthermore, play a key role in providing families with accurate and adequate knowledge and skills, empowering families in the process of adaptation. Obtaining truthful information is central to families' adaptation processes, especially when families are compelled to change their patterns of functioning. Adherence to the treatment regimen is a stringent task for families, often requiring that the existing patterns of functioning and routines are modified to accommodate the illness. Warning families of the changes in routine and the need for newly instituted patterns of functioning that support the management of the diabetes can assist families to make the necessary changes sooner, thereby enhancing their adaptation to the illness.

The importance of the family and the child with type I diabetes accepting the condition is crucial in the successful management of the illness. Practitioners can emphasise this with both families and patients, as there is not always an understanding of the negative consequences of non-compliance in the treatment of a chronic illness such as diabetes. Despite the fact that diabetes has far-reaching negative health implications for the patient, the correct management of the illness can result in good quality of life for the patient. Providing hope in this regard can also play a significant role in mobilising families and their children with type I diabetes into action.

Regarding future research, it is recommended that the siblings of children living with type I diabetes be included as research participants, since they also have to adapt to life with type I diabetes. It is also important that future research include a longitudinal component, as the process of resilience is best observed over time.[21] It is furthermore suggested that more extensive and a wider array of studies be conducted, with a focus on resilience in families that live with other chronic medical conditions. This could be valuable, not only to families, but also to health practitioners, who often treat a variety of conditions. Research of this nature could highlight possible differences and/or similarities in strength factors that families utilise in their endeavours to adapt to a chronic medical condition.

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