Developmental Risk and Resilience Factors for Juveniles with Type 1 Diabetes Mellitus

Purpose and scope of the essay

This essay discusses physiological, psychological and social risk factors for the life-span development of juveniles with Diabetes Mellitus Type 1 (DM1). Protective factors are also discussed in these respective areas.

DM1 is disease characterised by early onset. Approximately 85% of DM1 patients are diagnosed under the age of 18 (Laing et al 1999)[1]. Juvenile DM1 patients have more significant developmental risk factors than the general population. They also have a higher morbidity and death rate than diabetes patients who acquire the disease later on in life (Daneman 2005). Further, it appears that individual developmental risk factors facing juveniles with DM1 are multiplicative and interlinked.

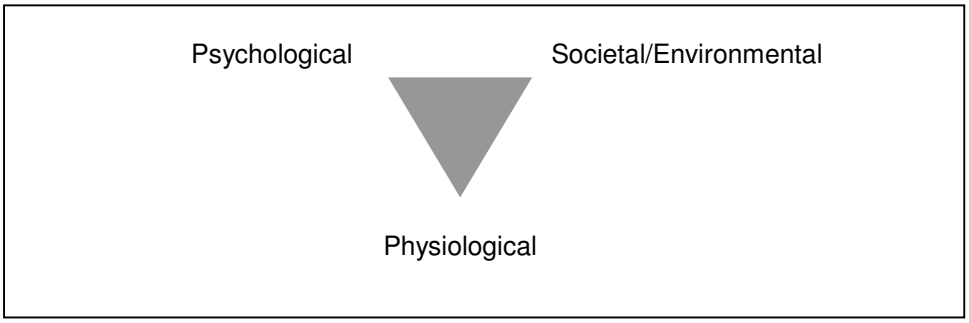


Figure 1.

[1] Based on a UK study where 23 752 patients contributed a total of 317 522 follow up years. Australian data from AIHW (1999) has its drawbacks given the national register is smaller and AIHW admits historically misclassifications may have occurred.

Young people diagnosed with DM1 are asked by their medical care practitioner to implement a complex regime of insulin injections and monitoring activities for an indefinite period. The disease is therefore referred to as 'chronic'.

For the purpose of the essay, developmental risk is viewed mainly from the perspective of lifespan development (with particular reference to Erikson's epigenetic model), with the focus juvenile age group being from birth to 18 years. The Erikson model tasks juveniles with achieving 'trust', 'autonomy', 'initiative', 'industry' and 'ego identity' during this period. Then, in adult life, they are tasked with achieving 'intimacy', 'generativity', and 'integrity' (See figure 2, at back, sourced from Robins, Chattergee & Canda 1998: 200).

Physiological Factors

The aetiology of DM1 is unknown, but is commonly thought to be genetic predisposition combined with environmental trigger factors. The cause of lack of function is thought to be a wayward immunological response that attacks and destroys beta cells in the pancreas (Laron 2002).

One of the roles of the pancreas is to regulate blood sugar via the secretion of insulin. DM1 diabetics need to use a man-made form of insulin administered intravenously in order to allow for proper conversion of sugars.

Early detection and the insulin regimen: Protective factors

Pre-adult DM1 suffers will experience morbidity or death within a short time if they do not implement an insulin injection regimen. Symptoms (such as thirst) are usually recognised by a concerned parent and the disease diagnosed before serious damage is done by unregulated blood sugar (Travis 1976: 345)[2]. Education of school teachers and parents are therefore primary protective strategies. Quick diagnosis can prevent damage[3], and the presence of targeted screening for children in the onset risk group is a protective factor (Daneman 2005).

Insulin injections, although greatly prolonging life, are not a complete cure. Later complications unavoidable and can be classified in two broad categories: the microvascular and macrovascular.

Microvascular deterioration results in nephron damage (leading to end stage renal dysfunction), retinopathy (leading to blindness) and neuropathology (leading to loss of sensation). Macrovascular deterioration refers mainly to atherosclerosis (hardened veins and arteries) that can lead to heart attack, stroke and peripheral tissue damage. Heart attack is the main cause of death for diabetic patients overall (Daneman 2005).

From a life-span developmental perspective, juveniles with DM1 will be often be precluded from entering later developmental stages (eg. Erikson's stage 8) by morbidity and death.

[2] Other signs are frequent urination, severe hunger and weight loss.
[3] Early complications mostly result from diabetic ketoacidosis or severe hypoglycaemia (Daneman & Frank 1998). In a US study at the Children's Hospital in Pittsburgh diabetic ketoacidosis was responsible for 85% of early deaths (Scibilia et al 1986 quoted in Daneman & Frank 1998).

Regular and measured insulin treatment is a crucial (but imperfect) protective factor for the short and long term physiological wellbeing of the sufferer. Insulin injections are essential if the juvenile is going to develop quasi-normally into adulthood. Physiological developmental risk for diabetes is therefore closely tied to self-care, family care and the availability of quality external care. This leads on to a discussion on social environmental factors (including 'quality of care' issues) and psychological factors.

Medical advice against pregnancy: A risk factor

Pregnancy for female DM1 patients is advised against by medical practitioners, at any age. (Travis 1976: 365). This will interfere with Erikson's 'generativity' stage for females that he associated with child rearing (Robins, Chattergee & Canda 1998; see Fig 1). According to Erikson, their energies will need to be diverted into other 'altruistic' activities in order avoid 'stagnation'. However, it may be that child bearing is not currently seen as an important developmental event for females as it might have been when Erikson proposed his model in 1950.

Age at diagnosis: A risk factor

Compounding risk is the fact that children and young adults are less able than adults to manage complex medical routines. The younger they are at onset the less capable they will be to manage a routine. For this reason, one of the major factors mitigating against risk is the presence of external support (Travis 1976: 354). This is available in

the form of parental support and professional health care support. Peer support schemes are also available in some communities.

Social and Environmental Factors

Health care: A protective factor

'Quality of care' is a phrase which arose in medical literature in order to combat bureaucratic views of health care delivery. Quality of care means 'doing the right thing right' (Daneman & Frank 1998). In other words it means that the process of care for individuals is important, and that statistical health care outcomes and cost are not the only factors to be negotiated. The quality of care discourse is especially relevant to juveniles with DM1 because of the range of protective factors that stem from high quality decision making and appropriate intervention by external agents. (Daneman & Frank 1998).

Professional health care support is expensive and limited. By way of example, Harrison (2004), in a UK survey, found that up to a third of paediatric teams did not have a specialist nurse. Specialist nurses are trained to run "HbA1C" tests in order to ensure the children's blood glucose levels have been appropriately maintained over 2 or 3 months. Harrison also noted that where a specialist nurse was present, they had a case load double the recommended level.

Accessing quality care can be influenced by socio-economic status and location. Daneman & Frank, Travis and generalist authors (eg. Dhooper 1997:42; Liamputtong

& Gardner 2003: 170) all point to the relevance of socio-economic status to the provision of quality health care. For example poor parents are less likely to take their children to a clinic (Daneman & Frank 1998).

Parental care: A protective factor

Parental support seems to be a very important source of resilience, because of the early onset of DM1 in childhood or adolescence (Williams 1997). Factors that affect parental support are included in this essay's risk factor analysis.

The medical profession values independence in young patients, perhaps as a way to increase their chances of dealing with diabetes in later life (Williams). However, as Williams noted, in actual practice parents are caught in a clash of conflicting societal attitudes and advice. They risk criticism from their peers if they give their child independence and the child fails to maintain a good standard of care. On the other hand, the medical health care profession may criticise them if they are too closely involved in the routine of good care. Parental stress is a risk factor.

For instance, Lewin et al (2005) made a study of 28 mothers with children who were type 1 diabetic. Lewin et al used a survey instrument called Pediatric Inventory for Parents (PIP) originally used with parents of children with cancer. The inventory is designed to measure parental distress associated with childhood disease. The measure consists of 42 items such as *Communication With the Family/Medical Professionals* and *Emotional Functioning*. The PIP test results showed mothers with diabetic

children had higher levels of stress because of overall disruption of daily roles and their communication role:

> This finding suggests that illness-related stressors associated with a mother's role as caretaker are highly related to stress and state anxiety. It is interesting that, for mothers in this sample, disruption of their normal daily roles (e.g., caring for other children, employment obligations, financial responsibilities) was more robustly related to their overall state anxiety than was their involvement in providing medical care and helping their children with medical procedures. Parenting stress related to communication with the child, family, and healthcare team was also meaningfully related to state anxiety, with a medium effect size.

Lewin et al suggest support groups and stress management programs, or psychological services can help boost resilience.

Destigmatisation support and management: A protective factor

Diabetics may feel discriminated against by their peers who mistook insulin injections for drug abuse. They may also feel discriminated against by their dietary limitations in social situations (Travis 1976: 358). This may impact on their ability to develop a supportive self-affirming identity (a pubertal task in Erikson's model).

However, there is also much to be said about parents and teachers providing role model behaviour and encouraging the development of a self-accepting identity as protective factors. Strength to stand apart from peers as different may possibly have foundations in earlier stages in the Erikson model, such as 'Autonomy'. There is no reason why young diabetics cannot successfully integrate their insulin and dietary

regime as part of their identity and manage the stigma that arises from time to time. For example, one of the girls in William's study said :

> Yes, there was no real problem. I think one girl once said behind my back, 'Oh, I wish she wouldn't do injections in the lunch break' and I think that was all, but I knew the other girls wouldn't stand for that so I don't really care about what people think, you know. In restaurants sometimes I'll be sitting there sort of stabbing myself and there will be people looking, thinking, 'what's she doing that for?', but I don't care.

In contrast, one of the boys in Williams study, absolutely refused to inject or check blood sugar in public.

Peer Support : A protective factor

Some hospitals have instituted a voluntary 'buddy-system' for diabetics. This is seen as a protective factor although there is no data on how effective these systems are in practice (McPherson, Joseph & Sullivan 2004).

Psychological Factors

Independent and good quality self-care is seen by the medical profession as the major long-term protective factor for juvenile DM1 patients (William 1997). However, the majority of juveniles with DM1 seem not to develop good self-care skills.

Taxonomy of adult DM1 patients

Nouwen, Gingras, Talbot & Bouchard (1997, referred to as 'Nouwen et al') identified three clusters of adult diabetics. These clusters were validated as useful definitional classes for the diabetics surveyed[4]. These three groups were:

1. Adaptive copers, characterised by:
    a. less difficulties than other groups.
    b. less interference of disease in daily life.
2. Low support/low involvement, characterised by:
    a. low perception of spouse support.
    b. low confidence in the ability to self care.
3. Spousal over-involvement, characterised by:
    a. Perceived significantly higher levels of positive reinforcing behaviours by spouses.
    b. Perceived significantly higher levels of misguided support behaviours by spouses (eg. Nagging).

According to the study the classes were roughly equal, with adaptive copers leading (the approximate ratio was 4:3:3). The presence of substantial 'spousal over-involvement' and 'low support/low involvement' groups and the gender differences in these groups raises questions. Gender representations in these groups may link to pre-adulthood patterns of forced reliance on the primary care giver, who is usually the mother (Travis 1976: 359). A psychodynamic approach may be warranted. A hypothesis may be that diabetics transfer the dynamics of their parental relationships

[4] Approximately only 1 in 10 diabetics did not fit in these clusters.

onto their spouses. This hypothesis is supported by Williams' study on the impact of gender on juveniles with DM1.

Gender: a risk factor

DM1 has an equal incidence in males and females (AIHW 1999; Laing et al 1999), however different risk factors seem to exist around gender. Williams analysed a group of adolescents aged 15-18 years. The following table summarises her findings, and the findings of Nouwen et al.

Stage	Male	Female
Childhood and Adolescence (Autonomy, Initiative, Industry, Ego identity)	More likely to have their mother look after their health regimen (Williams)	More likely to have intentional bouts of non-adherence. (Williams)
Adolescence (Ego identity)	May associate diabetes as weakness in the development of a 'masculine' identity. (Williams)	More likely to have guilt feelings for non-adherence (Williams)
Adolescence (Ego identity, Initiative, Autonomy)	Better care of diabetes overall, perhaps due to more parental involvement. (Williams)	More independent, but more likely to have expectations put on them to be self-caring. (Williams)
Adolescence (Ego identity)	Possible less internalisation of themselves as "chronically ill". (Williams)	Internalisation of role as "chronically ill child" may result in more independent self-care. (Williams)
Adulthood (Ego Integrity, Generativity, Intimacy, Ego Identity)	More likely to end up in spousal over-involvement group. (Nouwen et al)	More likely to end up in the low support/low involvement group. (Nouwen et al)

Table 1. Gendered differences in juvenile and adult diabetic self-care with regard to Erikson's 8 stage developmental model.

Females and males seem to have unique risk factors that may arise from societal expectations of the gendered roles.

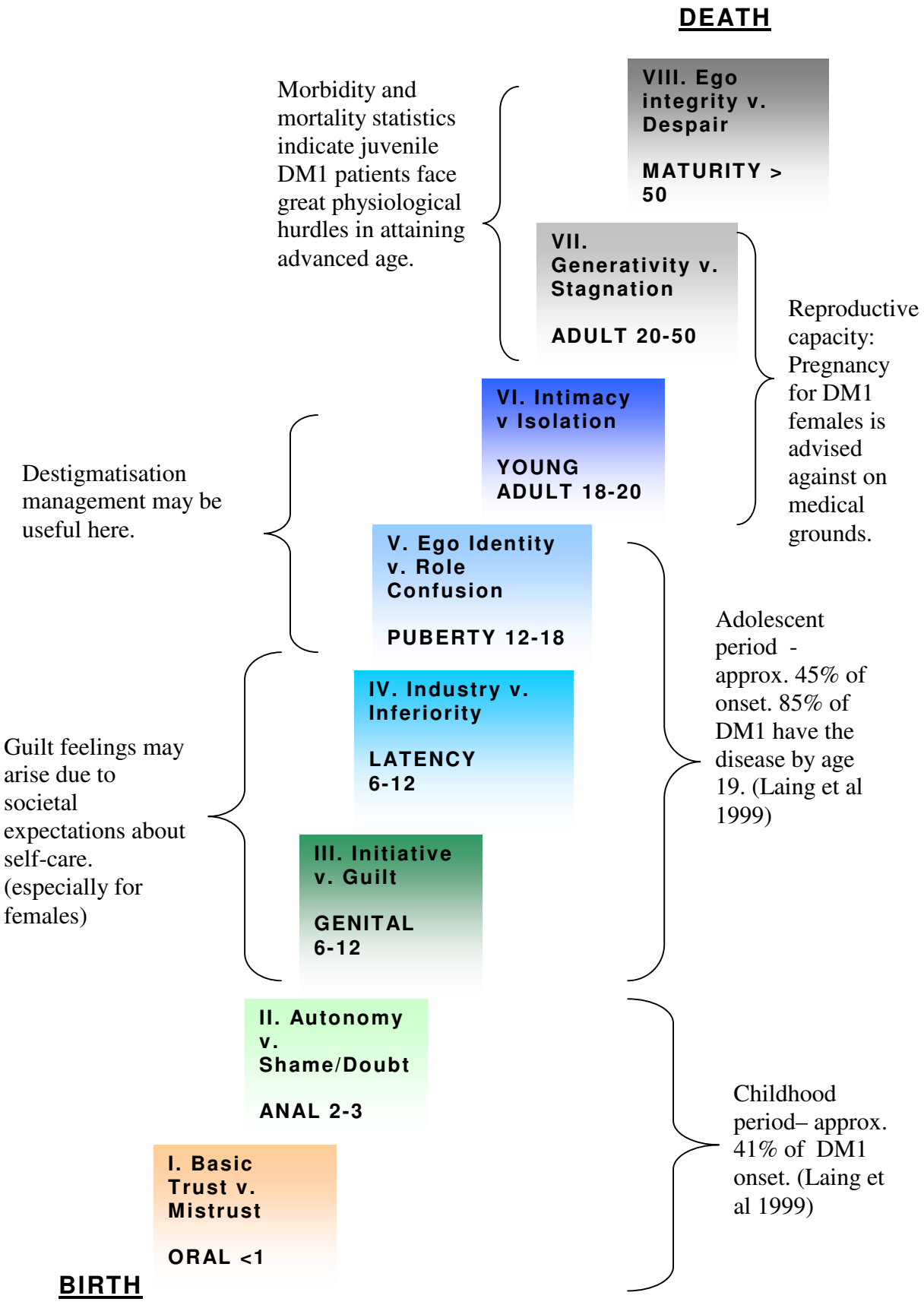
Conclusion

Juveniles with DM1 face many risk factors for development, with various mitigating protective factors. Physiologically they face a disease that is terminal without treatment. The protective factor of adequate treatment is not a cure, as DM1 slowly damages organs even with best available treatment. The treatment for DM1 requires a established system of insulin injections. Psychological developmental risks for juveniles with DM1 grow out of the need to draw in environmental support, especially in childhood. Social factors are parental support and provider health care. These two supports seem to be important protective factors for earlier stages of development. Delivery of non- psychologically harmful but significant external supports during childhood and early adolescence represents a challenge for parents and medical staff. The major protective factor for entrance and progression to later stages in Erikson's model seems to be adequate and consistent self-care.

ERIKSON'S EPIGENETIC MODEL OF LIFESPAN DEVELOPMENT –with ADDITIONAL COMMENTARY

(Partly sourced from Robins, Chattergee & Canda 1998: 200)

Figure 2



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