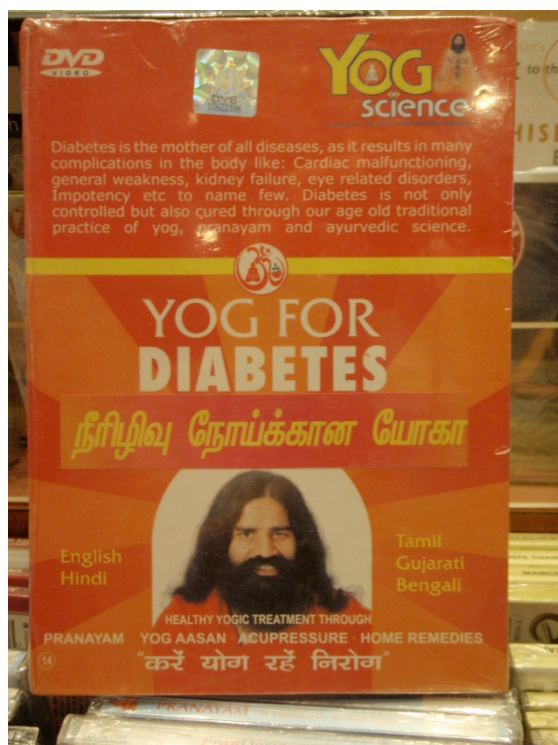


Stigmatization of children with chronic diseases, exemplified by type 1 diabetes mellitus.

Differences between India and Norway



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Contents

ACKNOWLEDGEMENTS	4
ABBREVIATION LIST	5
ABSTRACT	6
INTRODUCTION	8
METHODS	9
<u>I STIGMATA</u>	<u>10</u>
STIGMA THEORY	10
TYPES OF STIGMA	11
STIGMATIZED IDENTITIES	12
CHRONIC DISEASE AS STIGMA	13
IMPACT OF STIGMA	15
IMPACT OF STIGMA ON CONCEALABLE DISEASES	18
T1D AS A STIGMATIZING DISEASE	19
<u>II GENERAL ASPECTS OF NORWAY AND INDIA</u>	<u>21</u>
GENERAL ASPECTS OF NORWAY	21
DEMOGRAPHICS	21
BURDEN OF DISEASES	22
GENDER INEQUALITY	22
SOCIAL SECURITY SYSTEM IN NORWAY	22
GENERAL ASPECTS OF INDIA	23
DEMOGRAPHICS	23
BURDEN OF DISEASES	24
GENDER INEQUALITY	25
SOCIAL SECURITY IN INDIA	27
<u>III TYPE 1 DIABETES – GENERAL ASPECTS</u>	<u>30</u>
DEFINITION	30
DIFFERENT TYPES OF DIABETES MELLITUS	30
EPIDEMIOLOGY	31
ETIOLOGY AND PATHOGENESIS	31
CLINICAL PRESENTATION AND INVESTIGATIONS	32
ADDITIONAL INVESTIGATIONS	32
TREATMENT	32
EDUCATION	33
MANAGEMENT AND MONITORING OF GLYCEMIC CONTROL	34
INSULIN TREATMENT	35
NUTRITION	37
PHYSICAL ACTIVITY	37
COMPLICATIONS	37
ACUTE HYPOGLYCEMIA	37
COMA DIABETICUM WITH DKA	38
LATE COMPLICATIONS	38
OTHER	38
DIABETES IN NORWAY	39
THE NORWEGIAN CHILDHOOD DIABETES REGISTRY (NCDR)	39
EPIDEMIOLOGY	39

TREATMENT REGIMENTS	40
COMPLICATIONS	40
SPECIAL RESTRICTIONS AND ARRANGEMENTS FOR PEOPLE WITH DIABETES IN NORWAY	41
DIABETES IN INDIA	42
EPIDEMIOLOGY	42
TREATMENT REGIMENTS	42
COMPLICATIONS	43
IV STIGMA OF TYPE 1 DIABETES	46
STIGMA OF TYPE 1 DIABETES IN NORWAY	46
INNLANDET HOSPITAL ELVERUM, NORWAY	46
OBSERVATIONAL STUDIES	46
LITERATURE REVIEW	48
STIGMA OF TYPE 1 DIABETES IN INDIA	53
K.E.M. HOSPITAL PUNE, INDIA	53
OBSERVATIONAL STUDIES K.E.M. HOSPITAL	54
LITERATURE REVIEW	60
DISCUSSION	64
CONCLUSION	67

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Front page photos

Left photo: "India": Cover of a dvd, "Yoga diabetes" which claims to be able to cure diabetes through yoga, a dvd that we found at a mall in India.

Right photo: "Western world": Miss Florida 2010, using an insulin pump during the contest.

Abbreviation list

ADA: American Diabetes Association

CEDAW: Convention of the Elimination of All Forms of Discrimination against Women

CSII: Continuous subcutaneous insulin injection

DKA: Diabetic ketoacidosis

GAD: Glutamic acid decarboxylase

GDP: Gross domestic product

GNI: Gross national income

HDI: Human development index

HLA: Human leukocyte antigen

HbA1c: Glykosylated hemoglobin A1c

IA-2: Islet antibodies -2

IA-2B: Islet antibodies-2B

IDDM: Insulin dependent diabetes mellitus

INR: Indian Rupee

ISPAD: International Society for Pediatric and Adolescent Diabetes

K.E.M. Hospital: King Edward Memorial Hospital

MDI: Multiple daily injections

NCAER: National Council of Applied Economic Research

NCDR: Norwegian Childhood Diabetes Registry

NIS: National Insurance Scheme

NOK: Norwegian kroner

OGTT: Oral glucose tolerance test

OPD: Out Patient Department

PPP: Power purchasing parity

RBC: Red blood cells

RSBY: Rashtriya Swasthya Bima Yojna

SMBG: Self monitoring of blood glucose

T1D: Type 1 diabetes

T2D: Type 2 diabetes

WHO: World Health Organization

Abstract

Background

The term stigma refers to a mark of disgrace associated with a particular circumstance, quality or person, which leaves the object being unacceptably different from "the others". The individual suffers from stereotyping, labeling and devaluing from the society and from the people whom he or she routinely interacts. It could lead to a reduction in psychological wellbeing and physical health, as well as reduced health care seeking and inequitable treatment. It also carries shame, fear and guilt. Diabetes mellitus is a group of chronic metabolic diseases characterized by high concentration of glucose in the blood. The most common types are type 1 diabetes (T1D) and type 2 diabetes (T2D). The disease is associated with high morbidity and mortality. Quality of treatment is essential to control the disease and avoid complications.

Aims

The aims of this study were to find out more about stigma, how it presents and how it could affect chronic diseases, especially how it could affect children and adolescents with T1D. Stigma vary from different settings, it is socially constructed. Therefore we wanted to explore the differences in the presentation of stigma between Norway, a developed country, and India, a developing country.

Methods

In a semi-structured search in PubMed, Cochrane and Google, we searched for articles about stigma, diabetes, stigma of chronic diseases, stigma of diabetes in Norway, the western world and India. We used a questionnaire based on international guidelines to collect information about T1D in children less than 15 years of age. We interviewed health personnel at King Edward Memorial (K.E.M) Hospital in India and at Elverum Hospital in Norway, observed the daily routines and had conversations with patients.

Discussion

There are few studies found regarding stigma of diabetes mellitus in children in the western world including Norway, more studies are found from India which could be indicative of more stigma attached to T1D in India compared to Norway and the western world. To be diagnosed with T1D in India comes with a totally different range of problems than for children diagnosed with T1D in Norway. The children in India early experiences long term and short term complications and the mean age of death is low. In both countries the children with T1D experience different components of stigma, but the stigma is more pronounced and has worse consequences in India. In India there is an additional stigma of being a girl, which leads to a double burden of stigma for girls with T1D. There is also an economical issue, which makes the treatment of T1D difficult in India. This economical issue is not a factor in Norway, with a public health insurance system that secures treatment to all layers of the population.

Conclusion

The feeling of stigma is part of having diabetes. The consequences, however, vary largely between Norway and India. The feeling of being different and stigmatized affects the treatment of the child with T1D, which in turn affects the risk of both short and long term complications. Because of the possible serious consequences of diabetes complications, it is important to increase the general knowledge about diabetes, and thus try to reduce the stigma as much as possible.

Introduction

Background

In 2011, almost 500 000 children are estimated to have diabetes (1). Diabetes mellitus is a growing, globally important health issue. The children with T1D need lifelong treatment with insulin to prevent long term and short term complications, as well as death.

Before insulin was introduced in 1922, T1D was a fatal disease, with few children surviving more than 1-2 years (2). Today, almost one century after the discovery of insulin, the most common cause of death in diabetes in a global perspective is still lack of insulin. Many children die even before the diagnosis is made (3). More organizations and pharmaceutical companies have, however, started promising campaigns to increase the accessibility of insulin, and estimates show a strong increase of the availability of insulin the next years (4).

The potential stigma of T1D could worsen the situation for these children. It could lead to reduced psychological well-being and physical health, as well as reduced health care seeking and inequitable treatment. Hence, the quality of their treatment would be reduced. As the children with T1D need lifelong treatment and awareness to prevent complications and death, the reduced quality of treatment could have serious implications. The families to these children would also have to deal with the stigma, which could lead to changes in the family dynamics. Few studies have been published regarding stigma of diabetes in the western world, which could indicate that little or no stigma is attached to T1D. Also, some studies report diabetes to be one of the least stigmatizing chronic diseases. However, several children with diabetes do report feeling different and stigmatized. In other parts of the world, the situation is different. In India, getting the diagnosis of T1D includes a totally different range of problems than in the western world. There are more stigmatization attached to the diagnosis, and there is an additional stigma when being a girl with the diagnosis. Also, it has a huge impact on the family economy for an average family in India.

Our study is also part of a larger project. The aim of this project is a comparison between countries of strategies towards implementing internationally agreed guidelines of diabetes care in children. A group of 12 students went to different parts of the world for interviews and observational studies. We went to King Edward Memorial Hospital in India and Elverum Hospital in Norway. A part of this project was interviewing health care workers for information about how diabetes is diagnosed and followed up, so in that way be able to compare and explore differences between the countries.

Aims

The aims of this study were to explore stigma, how it presents and how it could affect chronic diseases, especially how it could affect children and adolescents with T1D. The stigma that attaches to any condition vary from different settings, it is socially constructed. Therefore we wanted to explore the differences in the presentation of stigma between Norway, a developed country, and India, a developing country. Hence, we wanted to explore the differences in stigma in T1D between Norway and India.

Methods

In a semi-structured search in PubMed, Cochrane and Google, we searched for articles about stigma, stigma of chronic diseases, stigma of diabetes in Norway, in the western world and stigma of diabetes in India. Search words were stigma, stigmatization, type 1 diabetes mellitus, T1D, diabetes mellitus, juvenile diabetes, complications, treatment, India and Norway in different combinations.

In India we spent some weeks at the Diabetes Unit at King Edward Memorial (K.E.M) Hospital in Pune, Maharashtra. As an observational study we followed the daily routines at the Diabetes Unit and had conversations with doctors, other health care workers and patients. In Norway we went to Elverum Hospital and did an observational study; we observed the daily routine and had conversations with the health care workers. We also had conversations with two young patients diagnosed with T1D. In these observational studies we wanted to explore how the clinics were run, how the children with T1D was managed, the rate of complications, treatment, and the general care of children with diabetes, as well as signs of potential stigma attached to T1D. All information from conversations with patients in this project is anonymized.

Prior to going to K.E.M. and Elverum Hospital, a questionnaire was developed, based on the 2009 International Society for Pediatric and Adolescent Diabetes (ISPAD)'s and American Diabetes Association (ADA)'s guidelines, designed to collect information about diagnosis, follow ups and complications in children with T1D. In both India and Norway we completed questionnaires by interviewing doctors and health care workers. Some of the information from these interviews has been used in our project.

I Stigmata

Stigma theory

Stigma is a Greek word that originally referred to a tattoo cut or burned in to the skin of criminals, slaves, or traitors in order to identify them as blemished or morally polluted persons. These people were to be avoided or shunned, particularly in public places (5).

Conventionally, stigma refers to any attribute, trait, or disorder that marks an individual as being unacceptably different from the "normal" people, with whom he or she routinely interacts, and that elicits some form of community sanction (6, 7).

The Concise Oxford Dictionary defines stigma as "a mark of disgrace associated with a particular circumstance, quality, or person" (8).

French sociologist, Émile Durkheim, which in 1985, was the first to explore stigma as a social phenomenon. He wrote, "Imagine a society of saints, a perfect cloister of exemplary individuals. Crimes or deviance, properly so-called, will there be unknown; but faults, which appear venial to the layman, will there create the same scandal that the ordinary offense does in ordinary consciousnesses. If then, this society has the power to judge and punish, it will define these acts as criminal (or deviant) and will treat them as such" (9, 10).

Erwing Goffman, one of the most influential sociologists of the twentieth century, defined stigma as "The phenomenon whereby an individual with an attribute is deeply discredited by his/her society is rejected as a result of the attribute. Stigma is a process by which the reaction of others spoils normal identity" (6).

The essence of these stigmas is of moral and judgmental nature, and the disgrace and the shame are more important than the bodily evidence of it. Labeling, stereotyping, separation, status loss, and discrimination can all occur at the same time and are considered components of stigma (11, 12).

Goffman used the idea of social identity to expand previous work done on stigma. When we meet strangers, certain appearances help us anticipate social identity, which includes personal attributes, such as competence, as well as structural ones, such as occupation (6). The person's social identity may include 1) physical activities 2) professional roles and 3) the concept of self. Anything that changes one of these, such as a disability, changes the individual's identity and, therefore, potentially creates a stigma (13). Goffman's theory defined stigma as something that disqualifies an individual from full social acceptance. Goffman argued that social identity is a primary force in the development of stigma, because the identity that a person conveys categorizes that person. Social settings and routines tell us which categories to anticipate. Therefore, when individuals fail to meet expectations because of attributes that are different and/or undesirable, they are reduced from accepted people to discounted ones – that is, they are stigmatized. Thus, to label a person as different or deviant by powers of the society is applying a stigma (6).

"Because stigma is socially constructed, it varies from setting to setting. In addition, individuals and groups react differently to the stigmatizing process. Those reactions must be taken into consideration, when planning strategies to improve the quality of life

for individuals with chronic illnesses. Although stigmatizing is common, not all individuals attach a stigma to their disability” (11).

Types of stigma

Stigma is a universal phenomenon and every society stigmatizes. Goffman distinguished among three types of stigma (6).

The first is the stigma of physical deformity. The actual stigma is the deficit between the expected norm of perfect physical condition and the actual physical condition. As an example, many chronic conditions create changes in physical appearances or function, which frequently create a difference in self- or other-perception (6).

The second type of stigma is that of character blemishes. This type may occur in individuals with AIDS, alcoholism, mental illness, or homosexuality (6). People infected with HIV, for example, face considerable stigma because many people believe that the infected person could have controlled the behaviors that resulted in the infection (14-17). The fear of stigma can be a major barrier to seeking treatment (11).

The third type of stigma is tribal in origin and is more commonly known as prejudice. This type of stigma originates when one group perceives features of race, religion or nationality of another group as deficient compared with their own socially constructed norm (6). Prejudice against individuals with chronic illnesses exists as surely as religious prejudice (11).

The three types of stigma may overlap and reinforce each other (14). Individuals who are already socially isolated because of race, age, or poverty will be additionally hurt by the isolation resulting from another stigma (11). Thus, people who are financially disadvantaged or culturally distinct (that is, stigmatized by the majority of the society) will suffer an additional stigma, that is, they will be more stigmatized, should they become disabled. For instance, as one study showed, poor women with HIV feared the stigma associated with HIV/AIDS more than dying of the disease (15).

Stigmatizing diseases can be further distinguished by their visibility and intrusiveness. Goffman's two levels of stigma: The discredited and the discreditable. Goffman describes those with disorders that are stigmatizing and that cannot be hidden or disguised (e.g., blindness) as discredited, and those with conditions that allow people to “pass as normal” (e.g., diabetes) as discreditable. Whereas the discredited may be confronted with problems of “impression management”, the discreditable may face difficulties of “information management”. People with visible stigmas are managing situations, whereas people with concealed stigmas are managing information about the self (6).

More recently, sociologists and psychologists have built on Goffman's theory to address the concepts of felt stigma and enacted stigma (16).

Felt stigma is the internalized perception of being devalued or “not as good as” by an individual. Firstly it is related to fears of having others treat one as different or of being labeled by others, even though the stigmatizing attribute is not known or outwardly apparent. The other component of felt stigma is shame (17). Individuals view themselves as discreditable (11).

Enacted stigma refers to behaviors and perceptions by others toward the individual who is perceived as different. Enacted stigma is the situational response of others to a visible, overt stigmatizing attribute of another (20, 21).

Hence, enacted stigma refers to actual discrimination or unacceptability, whereas the felt stigma refers to fear of such discrimination (18).

Jones et al. (19) added “the six dimensions of stigma” and correlate them to Goffman’s two types, discredited and discreditable.

1. Concealable – extent to which others can see the stigma
2. Course of the mark – whether the stigma becomes more prominent over time
3. Disruptiveness – the degree to which the stigma get in the way of social interactions
4. Aesthetics – others reactions to the stigma
5. Origin – whether others think the stigma is present at birth, accidental or deliberate
6. Peril – the apparent danger of the stigma to others

Stigma is prevalent in our society and, once it occurs it endures (20). If the cause of stigma is not removed, the effects are not easily overcome. An individual’s social identity has already been influenced by the stigmatizing attribute. A person with a history of alcoholism or mental illness continues to carry a stigma in the same way that a former prison inmate does (11).

Stigmatized identities

With one simple search in Pubmed with the word “Stigma” gave 7512 references. The related searches that came up were: “stigma HIV”, “obesity stigma”, “mental illness stigma”, “AIDS stigma” and “social stigma”. Surprisingly, or may not so surprisingly, only a few search results refer to diabetes mellitus. The classically stigmatized identities are epilepsy, HIV/AIDS, leprosy, mental illness and obesity.

The term concealable stigmatized identities/stigma covers a broad range of identities, including history of mental illness, rape, molestation, epilepsy, domestic violence, previous incarceration, HIV/AIDS and substance abuse (24, 25). Although these attributes differ considerably in their etiology, course and treatment, there are important similarities among all of these concealable stigmatized identities. Each is socially devalued and may render an individual vulnerable to prejudice and discrimination solely on the basis of this attribute (e.g. loss of status, employment discrimination, and personal rejection). These identities also have negative stereotypes associated with them (e.g. mental illness’ association with danger and instability) (21).

Disease per se is not generally regarded as stigmatizing, although some sociologists interpret it as a form of deviance, since to diagnose a disease in a person is to identify an imperfection or problem requiring treatment (16). But even if diseases are not invariably stigmatizing, some diseases and symptoms clearly are stigmatized. Which symptoms and diseases that are stigmatized vary historically and across cultures. Sontag has argued that different diseases have aroused particular feelings of dread or repulsion during different eras. In the present century in the developed world cancer has displaced tuberculosis in this respect (22). Also, it has been suggested that in contemporary developed cultures more stigma typically attaches to disorders for which people are considered culpable and to conditions of the mind rather than the body (23).

In these modern times we have come to believe that medicine is omnipotent and that, thanks to scientific and technical advances, it is now possible to combat any type of suffering by converting it into a disease. A new reality has come upon us, where there is

a growing tendency to convert healthy children or adults into patients, some would even say, to an extent that not having a diagnosis for any symptom is now unusual(35). Other authors would say that we are in the “age of iatrocacy”, that is, we live in a time when humanity is divided into two: patients and those who have not undergone medical tests or have not been to the doctor (35, 36). But it should be remembered that we may cause an iatrogenic harm by making an unnecessary diagnosis, or by translating any complaint made by a patient during a consultation into medical terms (35, 37).

Sometimes it is the authoritative application of a diagnostic label that “spoils” the identity of a person and renders him or her vulnerable to stigmatization. Even so, not all potentially stigmatizing labels are immediately unwelcome. That is, patients may be more relieved than disconcerted to learn of a diagnosis of multiple sclerosis after a protracted period of almost intolerable uncertainty (24). In contrast, the label “epilepsy” tends to be more instantly unwelcome and to leave individuals discreditable.

One community study of the reactions, experiences, and coping strategies of people with epilepsy has given rise to a hidden –distress model, which hinges on a distinction between enacted and felt stigma.

Firstly, the model asserts that adults with epilepsy, when diagnosed, typically generate an acute sense of felt stigma before any exposure to enacted stigma (children may be subjected to “stigma coaching” by well meaning, but overprotective parents) (18). Second, as a result of felt stigma, people tend to adopt a strategy of concealment and non-disclosure of their seizures and the diagnostic label. Third, as a function of successful concealment, few people are aware of people’s seizure and/or epilepsy, so that opportunities for, and instances of, enacted stigma tend to be few and far between. In the end, felt stigma typically proves more disruptive of people’s lives than enacted stigma (7).

Chronic disease as stigma

All types of stigma share a common tie: In every case, an individual who might have interacted easily in a particular social situation may now be prevented from doing so by the discredited trait. The trait may become the focus of attention and potentially turn others away (11).

Individuals with chronic illness present deviations from what many people expect in daily social interchanges...”the individual is at risk of being labeled as “different” by others” (11).

American and western values contribute to the perception of chronic illness as a stigmatizing condition. Magazines and television daily demonstrate that physical perfection is the standard against which all are measured, and this collide with the reality of chronic disease, that is, the reality of physical imperfection. Thus, a discrepancy exists between the reality of a chronic condition, such as diabetes and AIDS, and the social expectation of physical perfection (11).

A disease characteristic or one having unknown etiology, may contribute to the stigma of many chronic illnesses. In fact, any disease having an unclear cause or ineffectual treatment is suspect, including Alzheimer’s disease (25) and anxiety disorders (26).

Diseases that are somewhat mysterious and at the same time feared, such as leprosy, are often felt to be morally contagious (11).

Stigma can be associated with inequitable treatment. The relative severity of such inequitable treatment will often vary with the degree of severity of the stigmatized condition. For example, public policy about HIV/AIDS has acted both to increase accessibility to treatment and potentially to limit the civil rights of the stigmatized individuals (27). In addition, the shame, guilt, and social isolation of some stigmatized individuals may lead to inequitable treatment for their families. Because of the secrecy associated with being HIV-positive, affected clients and family members may not be able to access needed mental health care, substance abuse rehabilitation, or infectious disease therapies (28).

The majority of chronic illnesses are characterized by quiet, asymptomatic phases, followed by sometimes severe flare ups of symptoms (29). It can be critical for people living with chronic illnesses to access care regularly to prevent flare ups of symptoms and prolong asymptomatic phases. Regular care access might enhance quality of life of people living with chronic illnesses (30).

People with chronic illnesses may experience internalized, experienced and anticipated stigma within health care setting. People living with chronic illnesses report feelings of internalized devaluation, they are feeling shame, guilt and diminished self-worth (31), embarrassed and odd (32), and even dirty and diseased (33). People with chronic illnesses who have internalized, felt stigma and experienced stigma in health care settings may anticipate stigma in health care in the future. Thus, people living with chronic illnesses who internalize, experience and anticipate stigma within healthcare contexts may avoid accessing care and, in turn, experience decreased quality of life (30).

If felt and enacted stigma can pose threats to self esteem, security, identities, and life chances of those with certain diseases or symptoms, it can be difficult too for doctors and others charged to give treatment and care to patients. It has been suggested that good quality support in such cases requires doctors not merely to provide informed clinical interventions and advice, but to accept the principle of co-participation in care, which involves accommodating the notion of patients as decision makers; to promote an open agenda during consultations, which affords patients chances to raise matters they define as important; to adopt a holistic rather than a biomedical approach, with an emphasis on informing, advising, and helping people, not merely managing disease; and to develop counseling skills to complement technical skills, which presupposes an awareness of the salience of the phenomena like stigma and a learned expertise in advising on a range of strategies for coping (34).

A new or postmodern perspective maintains that the system of biomedical knowledge based on "natural" dichotomies such as normality/abnormality, healthy/pathological, social acceptability/social unacceptability etc, has arisen through a general cultural commitment to a discourse that dominates thinking and practice in the contemporary developed world. There is, it is contended, nothing sacrosanct or rationally compelling about this discourse: its dominance is a matter of chance. Advocates of disability politics are among those who have declined to accept or respond to conventional notions of abnormality, pathology, social unacceptability and, of course, disability (38).

Impact of stigma

Individuals with certain disorders can endure damaging experiences of enacted and felt stigma that impair the quality of their lives (7).

Stigma has an impact on both the affected individual and those persons who do not share the particular stigmatizing trait (11). Responses to stigma vary and will here be discussed from the perspective of the person living with stigma, the lay person, and the healthcare professional.

The individual living with stigma

Stigmatized individuals respond to the reactions of others in a variety of ways. The stigmatized individuals may be unsure about the attitudes of others and, therefore, feel a constant need to make a good impression. They could choose to accept society's or other's view of them, or reject other's discrediting viewpoints. Also, culture may limit the coping choices available. The cultural limitations are particularly seen in relation to disclosing a mental illness. In a study of West Indian Women coping with depression, Schreiber, Stern, and Wilson found that "being strong" was the culturally sanctioned behavior for depression, rather than disclosure (39).

Passing:

Passing oneself off as "normal" is one strategy used by individuals living with a stigmatizing condition. As an example, if the stigmatizing attribute is not readily visible, such as for asymptomatic diabetes or AIDS, there is an option to pretend to have no disability at all or pretend to have a less stigmatic identity (6, 38, 39). The process of passing may include the concealment of any signs of the stigma. As an example, some individuals refuse to use adaptive devices, such as hearing aids or insulin pumps, because this tells others of their disability (11). Another example is the abused client who provides reasonable explanations for bruises, swelling, and injuries. The practice of "passing" may significantly impair the health-seeking behavior of the abused individual, particularly where sociocultural barriers to disclosure exist (40).

Covering:

Covering is an individual's attempt to make a stigmatizing difference seem smaller or less significant than it really is, by deemphasizing the differentness. This is often done because of the potential threat and anxiety-provoking nature of disclosing a stigmatizing difference (6). Covering involves understanding the difference between visibility and obtrusiveness; that is, the condition is openly acknowledged, but its consequences are minimized. For example, individuals with special dietary requirements may deny or deemphasize the importance of maintaining the restriction in a social situation, even though they follow it. The goal of covering is to divert attention from the defect, create a more comfortable situation for all, and minimize the risk of experiencing enacted stigma (11).

Humor, used in a skillful and light-hearted manner by the stigmatized individual, is another form of covering, which may decrease the anxiety of others and avoid an awkward encounter. It neutralizes the anxiety-producing subject; therefore, the subject is no longer taboo and can more easily be managed (11).

Disregard:

A person's first response to enacted stigma may be disregard. That is, they may choose not to reflect on or discuss the painful incidents. Well adjusted individuals who are comfortable with their identity, have dealt with stigma for a long time, and choose not to respond to the reaction of others, may disregard it. One example of disregard as a coping strategy is the wheelchair athletes who disregard perceptions that their disabilities prohibit them from participating in strenuous, athletic endeavors. Anyone who has observed these well-conditioned athletes racing their wheelchairs up hills in competitions may find it difficult to consider them discredited (11).

To go public with a serious medical diagnosis is another example of disregard by acting in the face of negative consequences. One positive aspect of going public is the potential for assertive political action and social change. When famous people capture public attention by disclosing their personal struggles with a variety of conditions, they act positively to reduce enacted stigma (11).

There are a lot of famous people with diabetes who has come forward and told the world about their disease, and in this way helped raise awareness and lessen the stigma attached to the disease. One example is Ayden Byle, a Canadian athlete with T1D. He raises diabetes awareness through various fundraisers. Amongst these, he organizes an annually, nationwide run, Dash for Diabetes, which has raised thousands of dollars for diabetes. Also, he co-founded the Ayden Byle Diabetes Research Foundation and The Cure Diabetes Now Foundation. Another example is on the front page of this project, where you would find a picture of Miss Florida who used her insulin pump during the contest. This is an excellent example of disregard; she could still become Miss Florida, despite her disease. More famous people with diabetes can be found at http://www.dlife.com/diabetes/famous_people

Resistance and rejection:

Resistance and rejection are additional strategies used in response to stigma (41). That is, individuals may speak out and challenge rules and protocol if their needs are not met. Resistance or rejection can be used to preserve or bolster a more positive self-identity and effect larger societal changes. For instance, Franks, Henwood, and Bowden recently noted that resisting and rejecting were strategies used by maternal mental health clients. These disadvantaged mothers outright rejected or actively resisted the judgments of professionals who held negative opinions. Broader societal misconceptions, such as "all teen mothers are on welfare", also were rejected (42).

Isolation:

Human beings have a proclivity for separating themselves into small subgroups because staying with one's own group is easier, require less effort, and, for some individuals, is more congenial. This process of isolation can occur any time outsiders are seen as threatening or are reminders that the world is different from the in-group (11). Closed interaction from within may enhance one's feeling of normality because the individual is surrounded by others who are similar (43). However, this separation into groups tends to emphasize differences rather than similarities (11).

Staying with like-others may be a source of support, but some individuals with a disability or chronic illness could feel more comfortable when they are surrounded by nondisabled individuals. For instance, a young woman, disabled since birth, would feel better when around nondisabled individuals, because she has always considered herself

as normal. Her attitude reminds us to use caution when making assumptions about the perceptions of others (11).

Information Management and associative stigma

A personal concealable stigma is an identity that the self possesses, such as one's history of mental illness. In contrast an associative stigma is a stigma that a person possesses because of his or her close connection to a stigmatized other (6, 24, 51). Thus, in addition to the stigmatized individual, family members often acquire a secondary stigma as a result of association (6) and must deal with their own responses to situations of enacted stigma.

Research has shown that parents of disabled children; spouses, siblings and children of the mentally ill; and caregivers of people with AIDS all report feeling stigmatized, including feelings of shame, the need to keep the identity concealed, and the belief that others avoid (or may avoid) them due to their associative stigma (24, 52-54). Thus, family members who care for persons with AIDS share the stigma of AIDS and are discredited, resulting in rejection, loss of friends, and harassment (33, 44).

Information management is used by both the individual and loved ones in dealing with felt and enacted stigma. The world may be divided into a large group of people to whom they tell nothing and a small group of insiders who are aware of the stigmatizing condition. Healthcare professionals may use information management in an attempt to lessen the likelihood of stigma for a client. For example, listing a diagnosis of Hansen's disease or mycobacterial neurodermatitis then gives the option of revealing the alternate name of leprosy, with its accompanying historical stigma (11).

The lay person: Responses to and effects of stigma

An individual's responses to a stigmatized person vary with the particular stigma and the individual's past conditioning. Society specifies the characteristics that are stigmatized, thus, it also teaches its members how to react to that stigma. Differences between groups based on nationality and culture have been found in attitudes toward those with disabilities (45, 46). In the way that children learn to interact with others who are culturally different by watching and listening to those around them, they also learn how to treat chronically ill or disabled individuals by incorporating societal judgments. Sadly, these reactions are often negative (11).

Devaluing:

Devaluing is seen when people believe that a person with a stigma is less valuable, less human, or less desired. Unfortunately, many of us practice more than one kind of discrimination and, by so doing, effectively reduce the life chances of the stigmatized individual (6). Devaluing results in enacted stigma, such as using words as cripple or moron, or by categorizing individuals as inferior or even dangerous (11).

Stereotyping:

Categories simplify our lives. Instead of having to decide what to do in every situation, we can respond to categories of situation. Stereotypes are a negative type of category, that is, they are a social reaction to ambiguous situations which allow us to react to group expectations rather than to individuals. When individuals meet those with physical impairments, expectations are not clear (44). People often are at a loss as how to react, so placing the individual with chronic illness in a stereotyped category reduces the ambiguousness toward him or her and makes the situation more comfortable for

those doing the stereotyping. Much less effort is required to sustain a bias than is required to reconsider or alter it (11).

Using stereotypes to understand individuals decreases our attention to other positive characteristics (45). Categorizing tends to make one see the world as a dichotomy. For example, people are categorized as either mentally delayed or not, even though mental capabilities exist on a continuum, with all of us falling somewhere along the line.

Labeling:

As earlier mentioned, to label a person as different or deviant by powers of the society is applying a stigma (6). In general, labeling theory is the way that society labels behaviors that do not confirm to the norm. The label attached to an individual's condition is crucial and influences the way we think about that individual (11). For instance, the diagnosis of AIDS is a powerful label, which could possibly result in loss of relationships and/or jobs. People with learning disabilities may not mind being called slow learners, but the same people may be offended by being called mentally retarded (41). Their response indicates that they see this latter term as a negative label (11).

Professional responses: Attitudes and perceptions of stigma

In the United States, most healthcare professionals share the American dream of achievement, attractiveness, and a cohesive, healthy family. These values influence our perceptions of individuals who are disabled, chronically ill, or otherwise considered "less than normal". Although the factors that contribute to these individual differences vary, the consequences of stigma associated with chronic illnesses are similar in different health conditions and cultures (46). Therefore it is not surprising that society's values and definitions of stigma affect the attitudes of healthcare professionals (11).

Impact of stigma on concealable diseases

Stigma has large and varied effects on people's life outcomes (47, 48).

The stigmatized identities can be both concealable and visible (referring to Goffman's theory of the discredited versus the discreditable).

"At the broadest level, living with stigma – both visible and concealable – encompasses issues of identity and self definition (centrality, salience, collective esteem), treatment and relationships (anticipated stigma, experienced stigma), outcomes (psychological distress, health, achievement, employment), and the social context in which people live (cultural stigma). The good news of stigma research is that many people, despite living in a culture that often devalues them, can be happy, resilient, and well adjusted" (21).

Stigma scholars have long linked stigmatized identities to increased psychological distress (21). Quinn & Chaudoir studied the impact of stigma on psychological well-being (measured as depression and anxiety) and physical health in patients with concealable stigmatized identities, such as diabetes or AIDS. A concealable stigmatized identity is an identity that can be kept hidden from others, but carries with it social devaluation (49).

Quinn & Chaudoir related the psychological distress and health in patients with concealable stigmatizing identities (such as AIDS and mental illness) to four important stigma-related components, three of which were at the intraindividual level, and the fourth one at the external level (21).

A) Intraindividual level

1) Anticipated stigma refers to the degree to which individuals expect that others will stigmatize them if they know about the concealable stigmatized identity. How much devaluation and prejudice does the individual expect if his identity were to be revealed? Often also called felt stigma (see above) or perceived stigma. People with concealable stigmatized identities may not know exactly how others will react if they reveal the identity, oppose to people with visible stigmatized identities. They do know, however, the negative stereotypes about their group (21). People often learn negative stereotypes before they acquire a stigmatized identity, and it is difficult to unlearn those stereotypes once one gains the identity (50). Thus, people with concealable stigmatized identities know the negative stereotypes about their group and may even recall times when they themselves have discriminated against people with their identity. Also, because their identity is hidden, people with concealable stigmatized identities may often be in the position to witness disparagement of their own stigmatized group (51).

2) Centrality: This refers to how central the concealable stigmatized identity is to the self. Identities can be more or less self-definitional, and this is also true for stigmatizing identities (21).

3) Salience: Stigmatized identities also vary in the extent to which they are salient to the holders of the identities. To the extent that people are frequently thinking about the concealed identity, the stigma is a more important and salient part of their lives (21).

B) External level/ cultural stigma

Different types of identities are culturally devalued to different degrees. The level of cultural stigma is determined by the community or culture in which a person is living, not by the individual him - or herself (21).

Different stigmatized identities carry with them different levels of social devaluation. Previous research on stigma has shown that the more people believe that others devalue their group, the worse their psychological well being (21).

The studies of Quinn and Chaudoir showed that increased anticipated stigma, greater centrality of the stigmatized identity to the self, increased salience of the identity, and possession of a stigma that is more strongly culturally devalued all predict heightened psychological distress in people with concealable stigmatizing identities. They also showed that anticipated stigma and cultural stigma were directly related to self-reported health outcomes (21).

T1D as a stigmatizing disease

Goffman refers to diabetes as a "potential stigma" (6).

Stigma associated with T1D has not received much empirical attention, this might be due to the characteristics of the disease; it is not visible and apparent to all, at least as long as you manage it properly (49, 52). Diabetes is not immediately visible or necessarily known for others but the closest family and friends, and parts of the health care. Another factor that influences stigma is controllability; conditions that are viewed as being highly controllable (for which the stigmatized individual can be held responsible) are likely to receive more devaluation than those whose origins are

uncontrollable (53, 54). That may be the cause why, for instance, AIDS is among the most heavily stigmatized chronic illnesses. T1D, however, is a genetic disease and therefore largely uncontrollable. So why is diabetes still to some degree stigmatized? It may be due to the fact that people with diabetes must receive insulin from external sources to prevent possible complications, this creates a definite possibility for devaluation, as reliance on medical treatment for survival is a stigmatizing attribute (6, 52). It may also be due to the treatment regiment required that are often noticeable by others, like administering insulin, eating at specified times etc. In addition, the symptoms of hypoglycemia are highly visible. These may all contribute to the potential for stigmatization (52).

II General aspects of Norway and India

General aspects of Norway



Norway is situated north in Europe and has 4,812,000 inhabitants (55). The capital is Oslo. The major ethnicity in Norway is non-Hispanic white. In 2010, 12 % of the inhabitants in Norway were of immigrant background, the amount of immigrants increasing the past 50 years, from 1.4% in 1950 to the amount of 12 % today (56). Main religion in Norway is Protestantism – 86 %, other religions are Pentecostal, Roman Catholic, other Christian and Muslims (57).

Demographics

Life expectancy in Norway was in 2009, 83 years for women and 79 years for men (55). The life expectancy was in the end of the 1800's about 50 years, and has since then steadily increased. Decreased infant mortality, better living conditions with better hygiene, better housing and nutrition, development of vaccines and treatment have all contributed to this. Some geographical differences exist, the life expectancy varying with 3-4 years in different counties. Even in Oslo the life expectancy vary with 10-12 years in different parts of the city. Life expectancy also varies with educational levels, men with a high education and income live 7 years longer than those with only primary education, for women the difference is 5 years (58). Norway is among the 8-10 countries in the world with the highest life expectancy. Infant mortality rate was, in 2004, 2/1000 living births (58, 59).

Human Development Index (HDI) was in 2011, 0.943, ranking Norway as Very high human development. This puts Norway as number 1 on the HDI ranking. Not surprisingly, Norway is way above the world average HDI (in 2011 being 0.682) (60).

Human Development Index (HDI) measures the average achievements in a country in three basic dimensions of human development; a long and healthy life, access to knowledge and

a decent standard of living. Data availability determines HDI country coverage, the number, to the extent possible, being calculated based on data from leading international data agencies and other credible data sources available (61).

Economy and poverty

The mean income in a Norwegian household, after paying all taxes, was in 2009, 397 000 Norwegian kroner (NOK), wages contributing to around 65% of this (62).

According to The World Bank, no one in Norway live beyond their poverty line of \$1.25 a day (63). No children below 5 years of age are underweight (64, 65)

Burden of diseases

Norway is struggling more with non-communicable diseases than communicable diseases (66, 67). This is a result of the demographic transition, the transition from high birth- and mortality rates to the low birth- and mortality rates. (68). One of the causes for decreased mortality rate was decreased risk of infections, due to vaccinations, better personal hygiene and better managing of food (69).

Gender inequality

Norway has a gender inequality index at 0.075 (60), which is quite low (0 being best, 1 being poorest possible) (61). Norway is considered one of the most gender equal countries in the world, but still some challenges remain and new gender issues keep surfacing (70).

Today women and men have more or less equal levels of education, and women's participation in working life has increased dramatically since the 60's. Their income is still 60 % of men's, most largely due to the gender segregated labor marked in Norway; most women work in the public sector and most men in the private (71). Differences in wages are less, women earning in average 85% of men (72). Pregnant women are also discriminated against workplaces and equal pay is still an unachieved goal. Men also hold the majority of key political, economic and other decision-making positions (71).

Norway was quick to recognize women's right to make decisions about their bodies, including freedom of choice in terms of abortion, but more work is to be done in other areas. Many illnesses that women are prone to are not prioritized, and treatments are under-resourced (71).

Social security system in Norway

All residents with a residence permit in Norway are members of the National Insurance Scheme (NIS), a scheme for social security allowing people the right to pensions and benefits for unemployment, pregnancy and birth, single parental care, sickness and injury, disability, old age and death (73). For people with diabetes, NIS include coverage of insulin and equipment (74), You will have to pay a contribution up to a certain limit every year, which was NOK 1880 in 2011. When you reach the limit, you will automatically get an exemption card that covers all of the previously mentioned expenses fully. Children under 16 years of age do not pay any contribution at all and get everything fully covered (75). This means that the maximum amount of money a family

has to pay for their child aged 16 and above is around 0.5% of their income (calculated from mean household income).

If a child gets sick the parents will get the loss of income covered so that they can stay with the child at the hospital and follow them to consultations. Several other arrangements exist to cover for different extra costs having a disease (76).

General aspects of India



India belongs to the Southeast Asian region, the capital of India is New Delhi, the most populated city being Mumbai. India has 18 official languages (recognized by the Indian constitution), the most important being Hindi, Urdu, Bengali, Punjabi, Tamil, Telugu and English. Major religions are Hinduism (81 %), Islam (13 %), Christianity, Sikhism, Buddhism and Jainism. The main ethnic groups are Indo-Aryan 72%, Dravidian 25% and others 3%. While the national census does not recognize racial or ethnic groups, it is estimated that there are more than 2000 ethnic groups in India (77-79).

India has 1.2 billion residents, being the second most populous country in the world, accounting for 17% of the world's population. Following independence, India has pursued a policy of planned economic development until the early 1990's when shifted to a structural adjustment policies and liberalization. The economy then grew at a fast rate though concerns on equity and poverty persists. The country has recently become one of the world's fastest growing economies with an average growth rate on 8% over the past three years. It has emerged as a global player in several areas, including pharmaceuticals (80, 81).

Religion, caste and language are major determinants of social and political organization in India today. With more job opportunities in the private sector and better chances of upward social mobility, India is starting a social transformation in this area (79).

Demographics

Life expectancy in India was, in 2009, 63 years for men and 66 years for women (80), the numbers having increased during the last decades (59).

Human Development Index (HDI) for India was in 2011, 0.547– ranking India as Medium human development, number 134 out of 187 countries listed. The HDI has increased during the last decades, but is below the average in the world and also South East Asia as a region (82).

Economy and poverty

The per capita income, which is calculated by evenly dividing the national income among the country's population, were in 2011 expected to rise to Indian Rupee (INR) 54 527 in 2010-11 from INR 46 492 in the previous period; 2009-10 (83). Regional differences exists (84).

India has a multidimensional poverty index at 0.283% (82).

In 2005, 42% of the population lived below the international poverty line, that is, less than \$1.25 a day (set by The World Bank as a line to measure extreme poverty). 76% were living on less than \$2 a day (85). In local currency, \$1.25 is around INR 55 (86).

Even though the share of the population living below the poverty line has decreased from 60% in the beginning of the 80's to 42 % in 2005, the amount of people living below the poverty line has increased from 420 millions to 456 millions in the same period of time (85).

**The international poverty lines are based on a nationally representative primary household surveys conducted by national statistics offices or by private agencies under supervision of government or international agencies and obtained from government statistic offices and World Bank Group country departments (85).*

According to the national poverty line, 29 % of the population lives below the poverty line (1999-2000). National poverty lines are used to make estimates of poverty consistent with the country's specific and economic circumstances and are not intended for international comparisons. It reflects the local perceptions of the level of consumption or income needed to be poor (85).

There are regional differences within the country, based on the country's official poverty line, 42% of the people in rural areas and 26% of people in urban areas, lived below the poverty line in 2004/05 (87).

India is a country with tremendous differences between the rich and the poor. In 2010, the National Council of Applied Economic Research (NCAER) estimated that "India had more rich people than poor". The number of high-income households in India had exceeded the number of low-income households. By their definition low-income households has an income less than INR 45 000 per year, middle-income households has an income between INR 45 000 and INR 1.8 lakh per year, high-income households makes more than INR 1.8 lakh per year. By NCAER estimation there were 46.7 million high-income households, compared to 41 million low-income households in 2010 (88).

Burden of diseases

The health sector in India is diverse, and includes the modern system of medicine as well as multiple traditional systems. The rural health services infrastructure is widespread, starting with community workers, sub-centers, primary health centers,

community health centers, secondary level district hospitals up to medical colleges and their tertiary facilities. The private sector is large and unregulated (81).

Communicable diseases are still a big problem in India, accounting for about 38% of the disease burden with large variations across states. Maternal and child health issues are significant, including high rates of malnutrition (81).

In 1998/99, 47% of India's children below 3 years were underweight, of these were 18% severely underweight, the numbers estimated to approximately 60 million children. In addition, 26% were mildly underweight, in total, underweight afflicted almost $\frac{3}{4}$ of Indian children. The number of underweight children is nearly the double than in sub-Saharan Africa. Although levels of undernutrition have declined some during the 90's, this reduction lagged far behind achievements by other countries with similar economic growth rates (89).

Undernutrition directly affects many aspects of development, in particular retarding the physical and cognitive growth and increasing susceptibility to infection and disease, further increasing the probability of being malnourished. Malnutrition is estimated to be associated with half of all child deaths, the most common causes being malaria, diarrhea, pneumonia and measles. Child malnutrition is responsible for 22% of the country's burden of disease (89).

There are regional differences, the prevalence of underweight in rural areas are 50%, in urban areas 38%. It is also higher among girls (49 %) than in boys (46 %). This differences have widened during the 90's, most remarkable was that the reduction in underweight prevalence for males was 14% comparing to the 6% reduction for females (89).

Non-communicable diseases have evolved as a major public health problem, and accounted for 53% of all deaths of 30-59 year olds in 2005, and it is estimated to rise even more. The peak occurrence for these diseases in India is also a decade earlier than in western countries (81).

Gender inequality

Being born a girl in India is not easy. There are a declining number of girls in the country (90), and India has one of the lowest percentages of female population in the world (91). According to the 2001 census the overall sex-ratio is 933 women for every 1000 men (90). In some northern states, such as Haranya, the ratio dips to 861 to 1000 (91). The current all-India sex-ratio in 0-6 age group, also called the child sex-ratio is 927 girls for every 1000 boys. There are sharp variations in the child sex-ratio across regions, with the north and west of India showing larger deficits of girls (90).

“The high number of “missing girls” is indicative of the poor status of the girls – and of women. The overpowering desire to have a male child stems from economic and social factors: a son does not have to be married off with a dowry, he will grow up to be a breadwinner and support his parents, and he will carry the family name forward. A daughter is seen as a burden from day one” (90).

India has a long history of strong patriarchal influence in all spheres of life. This has translated into an obsessive preference for male offspring and discrimination against the girl child and women. It has spawned practices such as female infanticide, and later with the ultrasound imaging and amniocentesis, to female feticide and pre-conception

sex-determination in disfavor of the girls. It has also led to practices such as bride-burning and sati, and also neglect of the girls in terms of nutrition, education, health care and her overall development (90). Sati is a religious funeral practice among some Indian communities in which a recently widowed woman will have to self-immolate (setting herself on fire) on her husband's funeral pyre (92). The practice has been rare, since outlawed by the British in 1829 (93).

According to The United Nations Statistics Division, India has a gender inequality index at 0.617 (82).

India has several social legislations directed at changing social behavior and practices. They have laws that prohibit practices such as dowry, child marriage and sati. "While these laws have not entirely prevented these discriminatory and regressive practices, they do act as a deterrent" (90).

In 1994 came the Pre-Natal Diagnostic Techniques (Regulation and prevention of misuse) Act as a response to the declining number of girls as seen in the 1991 census' child sex-ratio. A gradual fall had been seen in the child sex ratio from 1961, with the sharpest fall in the child sex ratio from 1981 onwards. In 1981 the ratio was 962 girls per 1000 boys. In 1991 the child sex ratio was 945 girls for every 1000 boys. One of the reasons attributed to the lesser number of girls in the age group 0-6 was the practice of female feticide (90).

"Pre-natal diagnostic techniques like amniocentesis and ultrasonography have been used all over the world for detection of genetic abnormalities. However, in India, they are being misused for the past three decades for detection of the sex of the unborn child and subsequently for sex-selection – that is to eliminate fetuses selectively, if they are female" (90).

This law was necessitated because modern technology, like amniocentesis and ultrasonography, were being misused to eliminate female fetuses selectively. However, this Act was not followed up by effective implementation, and in addition to this, the need for smaller families led to even more intensified misuse of such technologies, cutting across barriers of caste, class, religion and geography to ensure that at least one child, if not more, were a son. With the advent of new sophisticated pre-conception sex selection technologies, the girl child's elimination started becoming more subtle, refined and probably also more socially acceptable. The 2001 census revealed a further drastic fall in the child sex-ratio, to 927 girls for every 1000 boys. The Act was then amended to the Pre-conception and Pre-Natal Diagnostic Techniques (Prohibition of sex selection) Act, which came into effect in February 2003. The stringent Act's purpose is to curb the abhorrent practice of sex determination and sex selection by prohibiting sex-selection before or after conception and to regulate the use of pre-conception and pre-natal techniques so that these are not misused for sex-selection. It is also meant to prevent the socio-cultural problems and population imbalances in the country that could derive from a declining number of girls and women in the population (90). Despite this Act, selective abortions of female fetuses still seem to be common in some areas (91).

Also survival is tough for girls: The mortality rate in girls under 5 years old is 79 per 1000, compared to 70 per 1000 in boys. Rates of immunization are much lower in girls than in boys (91).

Social security in India

India has a quite complex social security system. Private pension savings are becoming increasingly important (94).

Healthcare in India is largely financed by private out of pocket expenditure, only 2% of total health expenditure is accounted by private and social health insurance (based on data from World Health Organization (WHO)) (94). It is estimated that health insurance covers approximately 20% of India's labor force (95), also the range of illnesses covered is limited. The Employees State Insurance Scheme (ESIS) is a health insurance scheme for workers employed in the formal sector, it provides healthcare protection for approximately 3% of India's population and the quality of healthcare facilities is perceived to be in need of a substantial improvement (94). Less than 7% of the working force are organized or in the formal sector (96).

Several initiatives have been made to extend the coverage of community-based health insurance in rural India, including the National Rural Health Mission (NRHM) and the Rashtriya Swasthya Bima Yojna (RSBY), the former covering basic illness and primary care, the latter covering expenditure associated with secondary care. The RSBY is a government financed scheme for families identified as being below the poverty line, those included are eligible for healthcare benefits at accredited public and private healthcare providers of up to INR 30,000 each year. In 2010, 13 million households were enrolled (94).

	India	Norway
<i>Population (2009)</i>	1,198,003,000 (80)	4,812,000 (55)
<i>Life expectancy (m/f) (2009)</i>	63/66 (80)	79/83 (55)
<i>Probability of dying < 5 years of age (2009)</i>	6/1000 live births (80)	4/1000 live births (55)
<i>Human Development Index (2011)</i>	0.547 (82)	0.943 (60)
<i>Gross national income/capita (PPP int. \$) (2009) ***</i>	2930 (80)	59 250 (55)
<i>Multidimensional poverty index* (data from 2000-2010)</i>	0.283% (82)	n/a (60)
<i>Gender inequality index**</i>	0.617 (82)	0.075 (60)
<i>Total expenditure on health/capita (PPP int.\$) (2009)</i>	132 (4.2% of GDP) (80)	5395 (9.7% of GDP) (55)
<i>General government expenditure on health as percentage of total expenditure on health (2009)</i>	32.8 (97)	78.6 (66)
<i>General government expenditure on health as percentage of total government expenditure (2009)</i>	4.1% (97)	16.7% (66)
<i>Physicians /10 000</i>	6.0 (98)	40.8 (67)
<i>Obesity adults 20+ (m/f)</i>	1.3%/2.5% (98)	17.9%/21.6% (67)
<i>% Living in urban areas</i>	30% (98)	78% (67)
<i>Population median age (2011 est.)</i>	26 (99)	40 (57)
<i>Hospital beds/10 000</i>	9 (2005) (97)	35 (2008) (66)
<i>Age-standardized mortality rate non-communicable diseases per 100 000 (2008)</i>	685 (97)	363 (66)
<i>Age-standardized mortality rate communicable diseases per 100 000 (2008)</i>	363 (97)	27 (66)
<i>Incidence of T1D < 14 years /100 000</i>	4.2 (estimated 2011) (100)	33 (2010) (101)
<i>Mean years of schooling</i>	4.4 (102)	12.6 (102)

Table 1. Some general aspects - India and Norway

**The multidimensional poverty index identifies multiple deprivations at the individual level according to health, education and standard of living. To calculate it, it is being used data from household surveys. Each person in a given household is classified as poor or non-poor, depending on the number of deprivations his/her household experiences. These data are then aggregated into a national measure of poverty (61).*

***Gender inequality index is a value reflecting inequality in achievements between women and men according to reproductive health, empowerment and the labor market. The index shows the loss in human development due to inequality between women and men achievements. It ranges from 0, which indicates women and men are fare equally, to 1, indicating that women fare as poorly as possible in all measured dimensions (61).*

****PPP: Power purchasing parity: Using PPP instead of marked exchange rates to convert currencies, makes it possible to compare the output of economies and the welfare of their inhabitants in real terms – that is controlling for differences in price levels (85).*

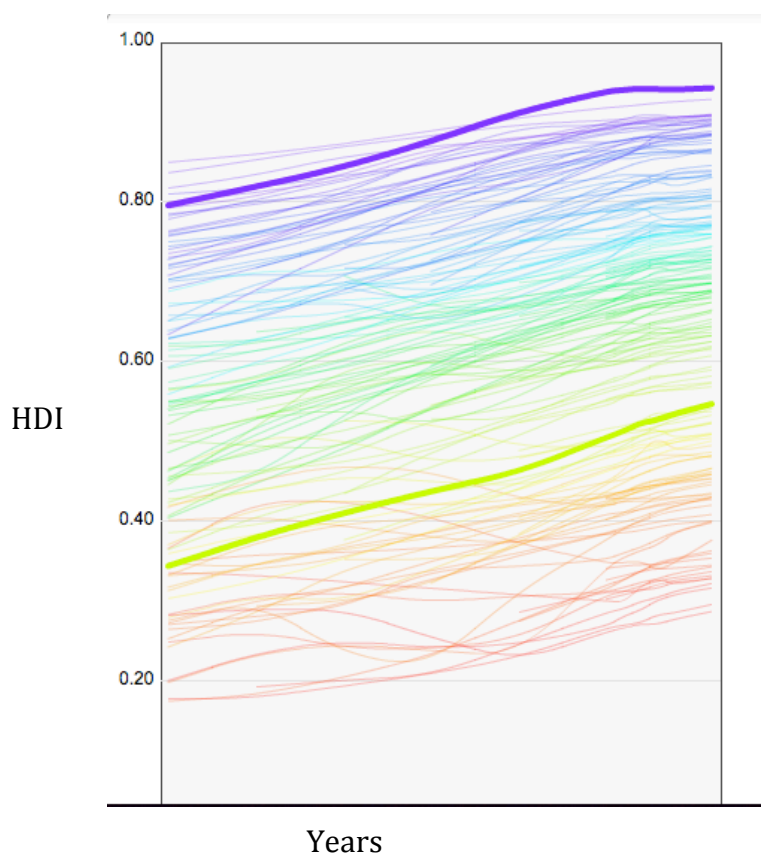


Fig. 1 Development of Human Development Index (HDI) 1980 – 2011 for Norway (blue thick line) and India (green thick line). Thin lines are the other countries on the list (103). (Regional and National Trends in the Human Development Index 1980-2011.

<http://hdr.undp.org/en/data/trends/> (25.01 2010))

III Type 1 diabetes – general aspects

Definition

Diabetes mellitus is a group of metabolic diseases, characterized by chronic hyperglycemia, due to a defect secretion of insulin, action of insulin, or both (4). Diagnostic criteria are based on measurements of blood glucose, in addition to presence or absence of symptoms (104, 105).

1. *Symptoms of diabetes + random plasma glucose ≥ 11.1 mmol/l (200 mg/dl)**
 - a. *Random is defined as any time of the day without taken into account when last meal was.*
2. *Fasting plasma glucose ≥ 7.0 mmol/l (126 mg/dl)***
 - a. *Fasting is defined as no intake of calories last 8 hours*
3. *2-hour post load glucose ≥ 11.1 mmol/l (200 mg/dl) under an OGTT (Oral glucose tolerance test)*
 - a. *The test is to done as described by WHO, using a glucose equivalent with 75 g anhydrous glucose dissolved in water or 1.75 g/kg body weight to the maximum of 75 g.*

* *Corresponding values (mmol/l) is ≥ 10.0 for venous whole blood and ≥ 11.1 for capillary full blood and*

** *≥ 6.3 both for venous and capillary full blood (104, 105)*

Glycosylated hemoglobin A1c (HbA1c) may now also be used in the diagnosis of diabetes. According to WHO, providing that stringent quality assurance tests are in place and assays are standardized to criteria aligned to the international reference values. A value of 6.5% is recommended as the cut point for diagnosing diabetes (106).

Different types of diabetes mellitus

T1D is a polygenetic disorder acquired in childhood and adolescence. It may, however, occur at any age, even in the 8th and 9th decades of life, but there is a characteristic peak in incidence around puberty. It is associated with autoimmunity. T1D normally contributes to > 90% of the cases of diabetes in children and young people in the western world. 2-4% have one parent with diabetes (4).

T2D is also polygenetic, but has a later debut, most commonly from puberty and later on. It is associated with overweight. In most countries T2D is contributing to < 10% of the cases of diabetes in children and young people. 80% have one parent with T2D (4).

Other forms of diabetes are neonatal diabetes (insulin-requiring hyperglycemia first 3 months of life), mitochondrial diabetes (often associated with sensorineural deafness, characterized by progressive, non-autoimmune β -cell failure) and medicine induced diabetes (4).

From now on we will focus on T1D.

Epidemiology

In 2011 it was estimated that 0.03% of all children (0-14) in the world had T1D, that means over 490 000 children, with approximately 78 000 newly diagnosed cases each year. The annual increase incidence is estimated to 3% (1). T1D is overall less common than T2D, but is increasing each year in both rich and poor countries. In most of the industrial countries, the majority of children and adolescents with diabetes have T1D (107). However, only < 50% is diagnosed at the age 0-14 years (108, 109). The cases of T2D in childhood are also increasing in some countries (1).

The incidence of T1D vary around the world, the incidences for children < 15 years estimated to 0.1-0.6 / 100 000 / year in China and Venezuela to 57.6 / 100 000 / year in Finland (2011) (100). The prevalence is also varying within a country, and between different ethnical populations (110).

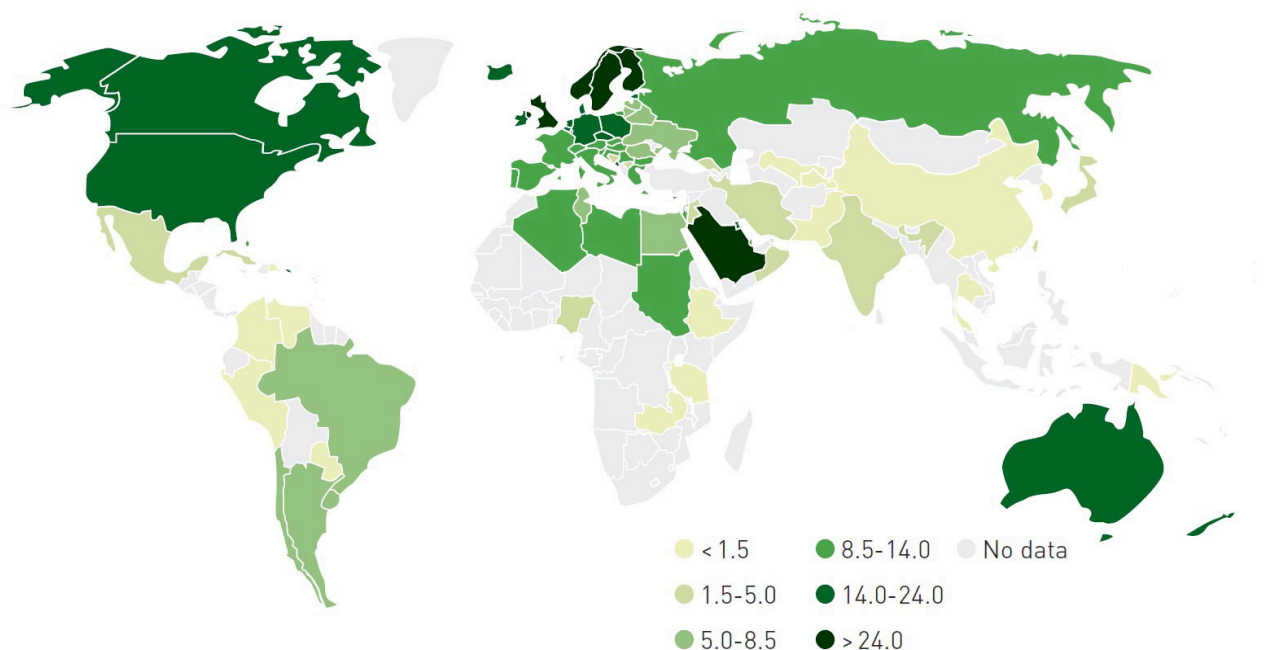


Fig. 2. New cases of Type 1 Diabetes (age 0-14 years) / 100 000 children/year 2011 (111) (New cases of T1D.

<http://www.idf.org/sites/default/files/da5/Map%202.5%20New%20cases%20of%20type%201%20diabetes.jpg> (31.01 2012))

Etiology and pathogenesis

The background of T1D is an absolute lack of insulin secretion. Most cases are due to a T-cell mediated selective destruction of the β -cells in pancreas. The destruction happens with variable speed, and symptoms occur when about 90% of the β -cells are destroyed (112).

Several serological markers exist, including glutamic acid decarboxylase (GAD), Islet antigen (IA)-2, IA-2 β and other insulin antibodies. In T1D these are present in 85-90% of individuals where fasting hyperglycemia are detected (113, 114).

Predisposition to autoimmune T1D are found in several genes. The strongest association is found on the Human leukocyte antigen (HLA)-genes, with both predisposing and protecting haplotypes (115, 116). People with an increased risk of developing T1D can often be identified with measurements of diabetes-associated autoantibodies, genetic markers and intravenous glucose tolerance testing (117-120).

Environmental triggering factors are mainly unknown (119, 120). Enterovirus infection has been associated with development of diabetes-associated autoantibodies in some populations (121, 122) and enterovirus has been seen in the pancreatic islands in individuals with diabetes (123-125).

When the clinical presentation is typical for T1D, but antibodies are missing, the diabetes are classified as type 1B (idiopathic) (4).

Clinical presentation and investigations

Diabetes in children most commonly presents acutely, with characteristic symptoms, like reduced general well-being, polyuria, polydipsia, visual disturbances and loss of weight, together with glycosuria and ketonuria. The blood sugar level can get so high that the child develop coma. There is often a typical history of excessive drinking and increased urination, excessive eating together with weight loss and general symptoms like fatigue, restless sleeping and irritability (126).

Findings are sparse, often limited to wasting and thirst. With coma and precoma, strong thirst, dehydration, reddened cheeks, abdominal pain with vomiting, tight abdomen, deep respiration, decreased alertness, shock and acetone smelling breath, may be seen. Diabetes in children has a tendency towards ketosis (126).

Additional investigations

Blood sugar, eventually HbA1c and urine testing of glucose, ketons, cylinders, nitrite and leukocytes are done (126).

After making the diagnosis, further investigations, treatment and follow-ups should be done at a children's ward/out patient clinic at a hospital. There several tests, like electrolytes and acid-base status, C-peptide test, investigations regarding secondary diabetes (Downs syndrome, Prader-Willi syndrome, Friedreichs ataxia etc.) are taken. The C-peptide test is measuring endogenous insulin production and indicates type of diabetes (126).

Treatment

The International Society for Pediatric and Adolescent Diabetes (ISPAD) guidelines

ISPAD published the first set of guidelines in 1995, and since then intensive treatment of diabetes in children has increased worldwide. Several national guidelines have also been made. The last edition from 2009 are based on drafts by international writing teams, modified by experts from several countries in different specialties, debated at yearly ISPAD meetings by members, and evaluated by members on the internet (3).

Education

“Diabetes education is not an element in the treatment, it is the treatment” (Dr. Elliot Joslin 1920).

Universal principles: “All children and young people have the right to a structural education by experts, who are helping them and their family to take control over their diabetes. The education is to be adjusted to each single individual, fitting their age, stage of diabetes, maturity and lifestyle. It should be adjusted to culture and to the single individuals needs. The ones carrying out the education should have access to continuous specialized training in diabetes education and educational methods. The education is a continuous process, which has to be repeated to be sufficiently effective” (127).

The education should be done by the time of diagnosis or when suitable for the patient, and then as needed as a continuous education. The education team should consist as a minimum of a diabetes nurse and a dietician (127).

Education should include explanation and information about the disease, insulin and how it works, practical skills of injecting insulin and testing blood sugar, diet and nutrition, explanation of hypoglycemia and how to recognize, prevent and treat it, what to do when getting sick and what to do when working out, goals regarding blood glucose and HbA1c and complications and how to prevent them. It should also be informed about diabetes associations or other supportive initiatives in addition to contact information (127).

This education should be followed by written guidelines and brochures adjusted to the age and maturity of the child, plus written material to the parents in an easily understandable way (127).

Infants and small children

Small children are completely dependent on parents and other caregivers for injections, food and monitoring. They often have unpredictable eating and level of activity (127). Normal infant behavior may be difficult to distinguish from diabetes related mood swings, and injections and glucose controls may be perceived as applied pain of the caregivers (128). Hypoglycemia is more common, and severe hypoglycemia may be more harmful (127).

School children

The children need to adapt to the transition from home to school, do develop self-confidence and to make relations to other peers (129). They should eventually be trained to set injection and to monitor, recognize and be conscious around hypoglycemic symptoms (130). The children should learn how to monitor glucose level and injections in a school setting (127). The parents should be given advices about the gradually development of their child’s independence with a gradually transition of more responsibility to the child (127, 129).

Adolescents

Many adolescents experience a deterioration in metabolic control (131-133), often attributable to erratic meal and exercise patterns (134, 135), poor adherence to treatment regimens (136, 137), hazardous and risk taking behaviors (138), eating

disorders (139, 140) and endocrine changes associated with puberty, leading to greater insulin resistance (141).

Adolescents have to learn to accept the important role of continued involvement of parents with simultaneously promotion of independent and responsible self-control, adjusted maturity and understanding. One should discuss emotional and friend conflicts, how to handle food indiscretions, disease, hypoglycemia, sport, smoking, alcohol, drugs and sexual health. It should be negotiated about aims and priorities, and to make sure the tasks are understood, accepted and is achievable for the adolescent. Development of strategies for transition to adult life should also be done (127, 142).

Management and monitoring of glycemetic control

Monitoring includes daily measurements of glucose at home together with periodical monitoring of total glycemia.

The goals for glycemetic control are (143):

- Manage with accuracy and precision the level of glycemetic control in each individual so that they can reach their most realistic goals
- Prevent both acute complications to hypoglycemia and chronic, microvascular and macrovascular diseases
- Minimize the effect of hypoglycemia and hyperglycemia on cognitive functions and mood
- Collect data for glycemetic control from each diabetes center to compare with local, national and international standards, to increase the standard of the diabetes team

Self monitoring of blood glucose (SMBG)

Self-monitoring of glucose levels gives immediate information about hyper- and hypoglycemia, and permit implementations of strategies to treat and avoid glucose levels outside the desired areas. It helps determine immediate and daily insulin needs and ease the insulin adjustment to reduce fluctuating glucose levels (143).

The frequency of measurements is associated with better HbA1c (144).

Frequency and regularity of measurement should be individualized with respect to availability of equipment, type of insulin regiment and how the child manages to identify hypoglycemia. Measurements with multiple injection therapy or insulin infusion therapy requires at least 4-6 measurements daily, and it should also be done frequent retrospectives on the results to detect patterns that require adjustments to the treatment (143).

Monitoring of urine glucose

In many countries this is the only possibility to measure glucose levels. If glucose exceeds the renal threshold, urine glucose reflects glycemetic levels over the past six hours (145). The method has several limitations, including uncertain correlation to blood glucose levels, lacking ability to detect hypoglycemia and monitor the response of the treatment to this, more difficult to identify glycemetic patterns and a lack of ability to help treatment during hyperglycemic crisis, because it takes time before the urine glucose levels register the changes (143).

Continuous glucose measurement

Recently it has been introduced less invasive facilities that measure glucose in the interstitial fluid every 1-20 minutes; continuous measurement. The devices are expensive, and are in many countries not available. In addition the insurance cover is limited. However, one hope that these devices will get more available eventually; this may lead to even lower HbA1c values and better the prognosis of children with diabetes (143, 146, 147).

Measurement of urinary or blood ketones

Such measurements should be done with cases of uncontrolled hyperglycemia, lack of insulin, inter-current disease and threatening diabetes ketoacidosis (DKA). Blood ketone measurements are more precise than urine ketone measurement, the latter are less useful in mapping and diagnosing DKA (143).

Glycosylated hemoglobin – HbA1c

Glucose is bound irreversibly to the hemoglobin molecule under the life cycle of the red blood cells and produce glycosylated hemoglobin – HbA1c (143). This reflects the glucose levels the last 4-12 weeks, the last week is not included because the glycosylation is reversible (148). The aim in the age group 0-17 years is < 7,5%, but each child should have an individually aim as close to normal as possible, without getting hypoglycemia. Every child should have a minimum of one measurement per year, ideally 4-6 measurements per year in younger children and 3-4 measurements per year in older children (143).

HbA1c can, to a certain degree, indicate the risk of long term complications (149, 150).

Insulin treatment

The insulin treatment started in 1922 with regular insulin. Eventually intermediate and long lasting insulin came, later insulin analogues, short and long acting (151).

Different regiments are in use;

Conventional therapy

- Two injections daily using a mixture of short or rapid and intermediate acting insulins (before breakfast and the main evening meal)
- Three injections daily using a mixture of short or rapid and intermediate acting insulins before breakfast; rapid or regular insulin alone before afternoon snack or the main evening meal; intermediate acting insulin before bed or variations of this (151).

Multiple daily injections (MDI)

More than three injections daily are called multi-injection therapy or intensive treatment (151).

MDI regimen combines a baseline level of insulin, using long-acting insulin analogues with pre-meal or snack boluses of rapid-acting insulin. This gives more stable glycemic control and fewer episodes of hypoglycemia than the conventional approach in children

(152-154). One trial also showed a trend towards lower HbA1c levels with MDI, although not statistically significant (152).

Insulin pumps

A type of intensive treatment.

Insulin pump, or continuous subcutaneous insulin infusion (CSII) is used more and more in children with diabetes (155). The way an insulin pump works is by delivering a basal rate of either rapid-or short-acting insulin subcutaneously. The rate of insulin given can transiently be increased as boluses for meals or glucose. The insulin is delivered through a subcutaneously inserted catheter. The pump does yet not include a “closed loop” system, where blood glucose values are determined and automatically used to reprogram the insulin pump, and they are therefore dependent on frequent blood glucose monitoring and readjustment of insulin infusion rates by the patient/parent (156).

Controlled studies in adults show that intensive therapy gives better glycemic control and reduce long-term sequels, compared with conventional therapy. Several meta-analyses have reported that CSII appears to provide slightly better glycemic control and decreased hypoglycemia than MDI (157-160).

Some of the advantages with the insulin pump are that it may be easier and more convenient than handling 6-7 injections a day, and it appears to improve quality of life in many patients (161-164). It may also give increased flexibility, especially with regards to meals and socialization (165), but, like MDI therapy, it requires increased blood glucose monitoring (156). Insulin pumps are more expensive to use than syringes and needles, and in many countries it is not affordable for most people (166, 167). Insulin pump treatment does not include long-acting insulin and pump failure can result in rapid onset of DKA. This is why frequent blood glucose monitoring is necessary (156).

Types of insulin in use

- Rapid-acting insulin (e.g. lispro, aspart, glulisine) and short-acting (e.g. regular insulin): Typically used as premeal bolus and also used by CSII as basal insulin levels.
- Intermediate-acting NPH (neutral protamine Hagedorn) insulin: Often uses in conventional treatment regiments (2-3 times daily)
- Long-acting insulin (e.g. glargine, detemir): Given 1-2 times a day, providing basal insulin levels (156).

Several attempts have been made to use immune modulation early in the course of T1D, but long-term effects are yet not documented (156).

Nutrition

The choice of insulin regimen also has to calculate the eating habits and life style of the child. A specialist in pediatric nutrition with experiences from children with diabetes should be a part of the diabetes team to teach, monitor and support the child, the parents, family, other caregivers and teachers (168). The monitoring of food intake is shown to give better glycemic control (168-171). Advices should include planning, content and timing of meals and snacks. The whole family should be included in the dietary changes (168).

Energy intake should be high enough to achieve optimal growth and maintenance of ideal body weight. Counseling should be adjusted regularly to fit changes in appetite and insulin regimens. The insulin should be adjusted to appetite and eating pattern (168).

Generally children with diabetes in all ages are heavier than children without diabetes, and girls in puberty are tending to gain more weight than boys (131). Advices regarding self-discipline, energy content in food, meal portions, regularly meals, fat and sugar intake in addition to physical activity is essential. Total daily energy intake is based on requirements for healthy children, with 50-55% carbohydrates (sucrose up to 10%), 30-35% fat and 10-15% proteins. Vitamins, minerals and anti oxidants is a need like in all other healthy children. Salt intake should be restricted like in all others (168).

Physical activity

Most studies have not shown a significant difference between physical activity and HbA1c (172-174), but one study has shown that frequent physical activity was associated with lower HbA1c without increasing the risk of severe hypoglycemia (175). In addition you have the effect in terms of weight control, reduced risk for cardiovascular diseases and increased well being (176). Exercising after meals may also be useful to minimize postprandial raises in blood sugar (177).

In people with diabetes the normal hormonal regulation normally initiated when you start exercising is not working, this often leads to hypoglycemia. The blood sugar values after exercise is however dependent on several factors and the blood sugar may both increase, stay unchanged or reduce (177).

Complications

Acute hypoglycemia

- The most common complication for children with T1D (178).
- Defined as blood glucose levels < 3.9 mmol/l (179, 180).
- Risk factors include younger age (181, 182), strict glycemic control (182-184), insulin regimen – conventional therapy including higher risk than intensive therapy (152, 166, 185-192), exercise, timing, frequency and carbohydrate content of meals, acute illness and psychological and socioeconomic factors and previously hypoglycemic episodes (193).
- Clinic
 - o Increased sympathetic activity; sweat, hunger, tachycardia, irritability

- Depression of cortical functions; somnolence, lack of consciousness, seizures (126).
- Treatment: Initially sugar
 - Measurement of blood sugar
 - Preventive: The child should always carry sugar
 - Treatment: Glucagon (subcutaneous if the child is has lowered consciousness or is unconscious). In hospital, glucose infusion fluid in an unconscious child (126).

Coma diabeticum with diabetic ketoacidosis

- Definition:
 - DKA: Blood sugar > 20-30 mmol/l, pH < 7.3 or bicarbonate < 15 mmol/L, ketonuria
 - Coma diabeticum (126).
- Occurs in 25-40% of the children with newly diagnosed T1D (study from Great Britain) (194).
- Most often due to an under dosage of insulin in relation to needs, e.g. fever, intake of large amounts of sweet food/drinks, glucocorticoids etc. (126).
- Clinical presentation: Polyuria and polydipsia, nausea and vomiting, red cheeks, abdominal pain, tight abdomen, dehydration and shock, acetone smelling respiration air, lowered consciousness, rapid and deep respiration (126).
- The patient may die from dehydration, acidosis and shock or hypocalcemia and the condition is severe (126).
- Although it should be largely preventable with established diabetes, reports from a childhood diabetes center in USA, 2005, reported an incidence of 8/100 patients years. Highest risk are uninsured or underinsured children, children with psychiatric disorders, poorly controlled diabetes and those who live in dysfunctional families (195).
- DKA is the leading cause of mortality and morbidity in children with T1D, the mortality rate ranging from 0.15-0.31% (196-198). Cerebral edema is the most important complication. It occurs in 0.3-1% of children with DKA and has a high mortality rate of 21-24% (199-202), the survivors often suffering from neurological sequels (203).

Late complications

Nephropathy, retinopathy and neuropathy are rarely seen in childhood and adolescence, at least not in the western world. The quality of diabetes care in children and adolescents can therefore not be evaluated due to late complications. Thus, the quality has to be measured by other goals, e.g. how many are screened by national and international guidelines, HbA1c and acute complications (101).

Other

- Mauriac syndrome: Uncommonly seen in the modern era of insulin therapy, but might be seen occasionally in children with poorly controlled T1D. It includes growth attenuation, delayed puberty, hepatomegaly with abnormal glycogen storage and steatosis and Cushingoid features (204-207).

- Depression: Negative psychological impact having T1D is well established, and is mainly manifested as depression (208-212).
- Eating disorders: In adolescence, T1D girls are at higher risk of getting an eating disorder than girls without diabetes (213, 214).
- Diabetic cataract may be seen early (215).

Diabetes in Norway

The Norwegian Childhood Diabetes Registry (NCDR)

Data on all children and adolescents with diabetes (age < 18 years) treated in pediatric departments in Norway are collected in The Norwegian Childhood Diabetes Registry (NCDR). It is created by the Norwegian Directorate of Health, economically supported by the South-Eastern Norway Regional Health Authority, and daily ran by the Children's clinic at Oslo University Hospital. The registry is cooperating with all the children's departments, doctors and nurses in Norway, working with diabetes in children and adolescents. In 2010, all the 27 pediatric departments treating children with diabetes participated in the NCDR. The mean participation rate in 2010, in children having the annual examination, was 95%. This number has increased every year since the beginning in 2001 (101).

One of the main tasks of the NCDR is to analyze and report back data to the participating hospitals. This is accomplished by giving every pediatric department an overview of their own data, and by comparing the different departments according to several data (benchmarking). The aim is to improve the quality of the diabetes care in children and adolescents in Norway (101).

Most of the numbers below are collected from The NCDR.

Epidemiology

The Nordic countries have the highest prevalence of T1D in the world, T1D being the second most common chronic disease in children in Norway. More than 95% of all children and adolescents with diabetes have T1D, and 50% with T1D get the diagnosis before 18 years of age (101).

In 2010, 325 children < 18 years were diagnosed with diabetes, 44% were girls and 56% boys. Of these, 99% had T1D. The incidence of T1D in children 0-14 years were 33 / 100 000 (101).

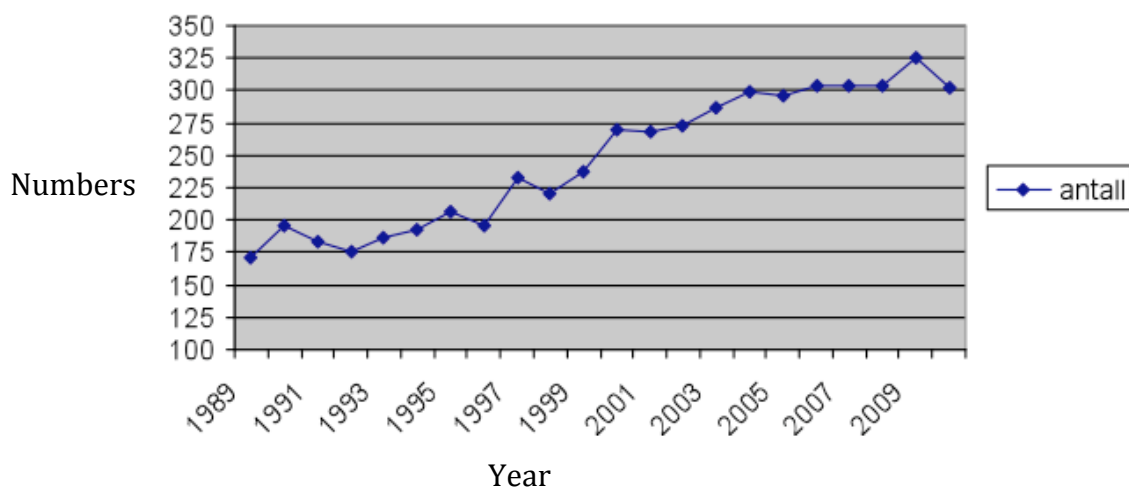


Fig. 3. Number of children and adolescents (age 0-14 years) with newly diagnosed Type 1 Diabetes in Norway 1989-2010 (216) (Annual report 2010: The Norwegian Childhood Diabetes Registry, 2011.)

Treatment regiments

There are ever increasingly changes in the diabetes care, new aids, new blood glucose meters, new insulin pens and new insulin pumps. Continuous subcutaneous blood sugar meters are another new tool. New and more expensive insulin analogues are being used, more are to come. The number of children using insulin pumps is increasing every year, also among the youngest children, the goal being better metabolic control and better quality of life (101).

In 2010, eight out of 21 children departments started treatment with insulin pump at the time of diagnosis. The proportion of the patients using insulin pumps have increased from 15% in 2002 to 57% in 2010, without an increase of severe ketoacidosis (101).

Complications

Acute complications

At the time of diagnosis, 19 % of the patients had DKA, of these 19% were mild, 12% moderate, 5% severe and the rest unknown (according to venous pH levels or bicarbonate levels). Around 5% of the patients are admitted to the hospital for DKA every year, the number being relatively stable from the start of the recording in 2001. The number of patients with hypoglycemic shock with unconsciousness (with or without seizures), have decreased steadily, from 14% in 2001 to 6% in 2010 (101).

Late complications and screening regiments

Late complications, like nephropathy, retinopathy and neuropathy are uncommonly seen in children and adolescents.

- **Kidneys:** Yearly screening with urinary examination from 11 years of age with 2 years of diabetes duration or from 9 years of age with 5 years of diabetes duration (101).

- **Eyes:** Yearly screening by an eye doctor from 11 years of age with 2 years of diabetes duration or from 9 years of age with 5 years of diabetes duration. In 2010, 0.2% had retinopathy, none had laser treatment last year (101).
- **Screening for other diseases:** Celiac disease and hyper- and hypothyroidism (101).

Mortality

Deaths in children and adolescents are seen, but are rare (101).

A Norwegian study reported an increased mortality risk in people with childhood onset T1D, compared with the general population. The overall standardized mortality rate (excess mortality compared with the background population) was 4.0 and was similar in males and females. The most common cause of death at ages < 30 years were acute metabolic complications of diabetes. From ages 30 years and onwards, cardiovascular diseases were the most common cause of death (30%), followed by violent death (28%). The mortality rate was 2.3 times higher in males than in females, but a higher proportion of the females had diabetes mentioned on their death certificate (217)

Measuring quality of diabetes care

HbA1c is the most important quality indicator of children's diabetes. It has nationally been relatively stable, and higher than desired at the last annual controls. In 2006 mean HbA1c in all children with T1D (age < 18 years) was 8.6% (8.1-9.3) (101).

During puberty, the treatment of diabetes meets special challenges. This is reflected in the measurements of mean HbA1c in different age groups; mean HbA1c is increasing with increasing age group. In adolescence you do not want to differ from your peers, this may cause difficulties measuring blood sugar and inject insulin, they also take over the responsibility for treatment themselves. In addition, the hormonal changes result in increased need for insulin, and together with bad compliance this is unfortunate (101).

Follow-ups and yearly controls

Most children and adolescents with diabetes have three or more controls at the children's outpatient clinic each year. One of these is called an annual control, being a standardized clinical examination including standardized questions. The results are sent to the NCDR. Each department will receive back a report on their own data and a national report with benchmarking results (101).

Special restrictions and arrangements for people with diabetes in Norway

People with diabetes may have trouble getting insurance or may have to pay a lot more than healthy people. They may also feel discriminated getting a job, but certain laws are made to avoid this (74). A few types of work are restricted, like passenger transport, commercial diving, police and fire brigade (218). They are also exempted from compulsory military service, and are not viewed as field capable (219). Regarding driver's license, they have special rules and have to take special precautions, like always carrying sugar while driving; they need an attestation from a physician (220, 221) and it is valid for 5 years only (as opposed to for lifetime for others). Rules for trucks are even more strict, license for minibus and bus are usually not given (221, 222).

Diabetes in India

Epidemiology

Diabetes is a big problem in India, but this is mainly T2D. The estimated number of people with diabetes in India is around 40 millions (with a population of more than 1000 millions), placing the country first when it comes to number of people with diabetes. T1D is however less common (223).

The incidence of T1D in children (0-14 years) is estimated to 4.2/100 000/ year, a number much lower than in Norway. No national diabetes register exist (224).

Treatment regiments

In general, management of T1D in India has a unique set of problems. Patient related factors include reluctance to take insulin injections and to measure blood sugar at home, poor economic resources, not being able to afford insulin, glucose strips and investigations and lack of facilities for proper storage of insulin. Other factors are a lack of qualified health care professionals and poor availability of insulin and strips for blood glucose measurements in smaller villages (225).

Syringes and pens are at present the most commonly used insulin devices in India (226). Most common are syringes, insulin pens are more expensive and therefore less used (225).

Two regiments are used:

Conventional insulin regimen: Most commonly used by T1D children. Consists of two injections of short and long-acting insulin, "split and mix" regimen. The glycemic control achieved is reasonably good, with a goal of HbA1c < 8.0 %. This regimen is the easier to explain, require less resources from the diabetes management team and is cheaper for the patient and family. It is still the most suitable regiment for the vast majority of the patients in India. Reports from one hospital in India in 2007 said that 95% of the children used this regimen (225).

Intensive insulin regimen, using separate basal insulin and insulin boluses for meals. Glycemic control is achieved better, with a HbA1c goal of < 7.5% and flexibility is greater, but it requires greater motivation and financial resources in addition the availability of an experienced team. Only a minor part of the patients are subjects for this treatment regiments.

MDI: By far the most common intensive regimen. Insulin pens are most convenient for multiple injections. The same hospital as above reported that 4% of their children used this regimen (225).

Insulin pumps: Mostly used by T2D patients, these constituting 80% of the insulin pump users. In India, the pumps are usually not reimbursable or covered by insurance, and the patient has to buy the pump and the consumables themselves, both being expensive, and few people can afford it (226).

In many cases children are treated with only a single dose of long-acting insulin, or doses with regular insulin without any basal insulin. Glucose monitoring is infrequent, home measurements of blood glucose and adjustments of insulin doses are rarely done.

In cases where strips are not affordable, patients are often encouraged to combine urine and blood sugar monitoring. Patient education is also not optimal, it may even be non-existent, and little information is given according to adjusting insulin or meal schedules or dealing with emergencies (225).

In India, the insulin types available for routine clinical use are the beef, porcine and human insulin. Even though beef insulin differ from human insulin in three amino acids, and thus is more immunogenic, it continues to be widely used in India, in view of its relatively lower costs (227). The costs of the different insulins, ranges from 65 Indian rupees for the bovine insulin with the human insulin costing from approximately 145 rupees to over 1000 Indian rupees for each dose of 10 mL (228).

Complications

It is few available studies solely focusing on the T1D complications and mortality in India.

Regarding incidence of T1D and associated complications among children and young adults, data retrieved from Karnataka Diabetes registry (1995-2008) showed that they had 1040 patients between the ages of 0 to 25 years. 88 % were below 50th percentile height, 95 % were below 50th percentile of weight and 10.7 % had poor glycemic control (measured as A1c >9 %). 5.2 % had neuropathy, 8.4 % had retinopathy, 8.6 % had nephropathy, 2.6 % had hypertension. Hypercholesterolemia and hypertriglyceridemia were found in 20.2% and 41.7% of the cases respectively and 18.1% had low HDL (High density lipoprotein). The percentage of patient with micro-albuminuria was 29.6%. Poor glycemic control, hypertension and duration were strong consistent predictors of all complications (229).

Another study from north in India reported a mean HbA1c of 8.2%. 52% had an HbA1c > 8%, and 10% had a value > 10%. The frequency of severe hypoglycemia was 3.3 episodes/100 patients years, and the frequency of DKA was 5 episodes/100 patient years. Retinopathy was reported in 22% and nephropathy in 18% in those with a diabetes duration of 5 years of more, mean age being 21.2 years and mean duration 10,2 years (230).

“Though the incidence of diabetes in the young is low in our population compared to the western population, the burden of diabetes is high due to large population in our country. In spite of our best efforts there are still a huge gap between the standard of care and practice. Majority of type 1 diabetics are not reaching the ideal glycemic targets.” (229).

Mortality

Regarding mortality in diabetes mellitus we found a study from a tertiary teaching hospital in northern India. They studied all deaths at the hospital during a period of 9 years, where they retrieved all of whom had died from diabetes mellitus. They found 741 patients who had died from diabetes during that period, where 41 had T1D, and 383 (52 %) were male (231).

This is the largest hospital-based study of mortality pattern in patients with diabetes from North India and presents two main findings: 1) the mean age at death in hospital is significantly lower than the life expectancy at birth in India; 2) infections and renal disease contribute to most deaths of people with diabetes in this part of the world (231).

In the study of patients with T1D, DKA was the second most common cause of death after infections, accounting for 42 % of the deaths. Also the study showed that DKA was the cause of death in 63 % of the patients with diabetes who were younger than 24 years, but overall it was a contributory cause of death in about 3 % of their patients with diabetes (231).

“Infections, alone or in combination with other causes, accounted for more than 40% of deaths in our study. The continued dominance of infections in causing mortality in our patients with diabetes may stem from the overall high incidence of infections in this part of the world, deriving from low literacy rates and poor public health infrastructure, and also the poor control of glycemia in people with diabetes” (232).

“Chronic renal failure was the second most common cause of death in our study, accounting for about one-third of deaths. It was also the most common “single cause” of death (15%). This reflects the generally poor glucose and hypertension control in these patients with diabetes” (231).

The life span of a patient with diabetes (both T1D and T2D) was shortened in their community, especially for women, who died on average 9.5 years earlier than their life expectancy at birth. In comparison, the men only lost 3.5 years of their expected life duration. The mean age at death for people with T1D was 29.61 years. In people with T2D the mean age of death was 60.66 years. Hence, the patients with T1D died earlier, and the female patients with T1D died at the youngest age with a mean age of death of 27.26 years (231).

“Seven percent of all deaths in our study occurred in patients younger than 40 years, most of whom had T1D. In the modern era of insulin and insulin analogues, very few young patients should, or do, succumb to acute metabolic complications of diabetes; however, in the underdeveloped areas of the world such as India, they continue to be susceptible to major morbidity and early demise “ (231).

Another finding of their study was that there were some differences in patients from rural and urban backgrounds, with patients of rural origin dying at a younger age, being more likely to have T1D and infections, and being less likely to have renal disease or cardiovascular disease (231).

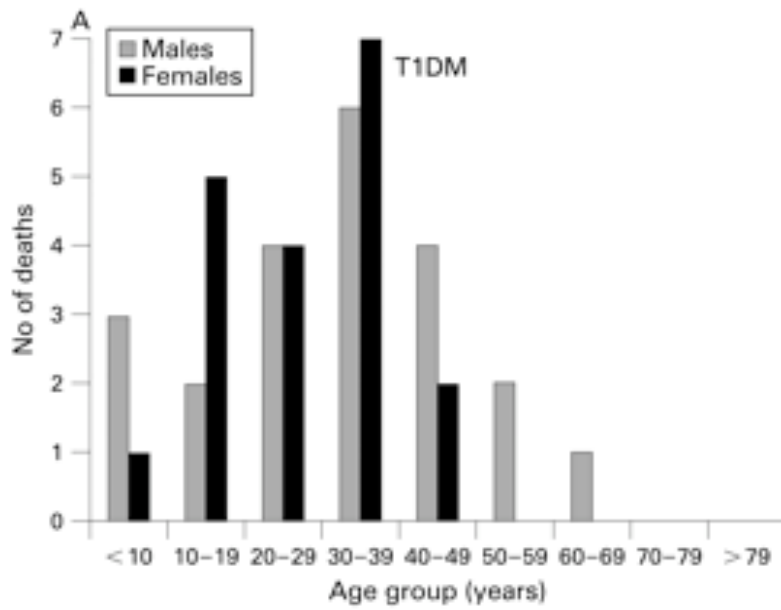


Fig 4. Age and sex distribution of the 41 dead subjects with type 1 diabetes (231) Zargar AH, Wani AI, Masoodi SR et al. Causes of mortality in diabetes mellitus: data from a tertiary teaching hospital in India. *Postgrad Med J* 2009; 85: 227-32.

IV Stigma of type 1 diabetes

Stigma of Type 1 Diabetes in Norway

Innlandet Hospital Elverum, Norway

Elverum Hospital is a part of Innlandet Hospital Trust, consisting of 8 hospitals. Children with diabetes are treated at the Childrens medical ward, which are separated in an outpatient clinic, intensive ward for newborns, and the children's Ward, for older children. Children with diabetes are mainly treated in the outpatient clinic (233, 234). The children are attending the pediatric department up to finishing high school. No adolescent department exist at this point (235).

Around 10-17 children < 15 years with T1D are admitted to hospital annually at the children's ward (235). There are a few more boys than girls followed up at the hospital (235).

There are no social activities arranged by the hospital (235), but The Norwegian Diabetes Association is arranging courses, social gatherings and theme evenings for children and adolescents with diabetes locally (236).

Observational studies

Observations made at the hospital

When the children are diagnosed, they are first hospitalized for between 10-14 days, depending on family relations and how safe the parents feel about the diabetes treatment. Only a few have DKA at diagnosis, 13% in 2010.

The pediatric department works interdisciplinary (diabetes team) according to the needs of each single patient. Three doctors alternate on having the outpatient clinics together with a diabetes nurse. Social workers and dieticians also participate in the diabetes team. A psychologist is no longer a part of the team. The children have the diabetic nurse as a contact person, in addition to a contact person on the wards.

After getting the diagnosis, diabetes education is given to the child, the parents and grandparents, as well as to other caregivers and to the school or kindergarden. It is organized individually and in groups and repeated at every check-up.

The hospital is using two types of treatment regimens, about 50% are on insulin pump and 50% on MDI. The hospital follows the ISPAD treatment goals, HbA1c aimed < 7.5%. Only a few patients achieve the treatment goals, 20% in 2010. The children attend check-ups every third months, and almost everyone attend their appointment.

The health care workers said that many children feel stigmatized and different. It still exists prejudice in Norway, one of these is that T1D is caused by eating too much sugar and unhealthy food. Old prejudice also exists about complications, including getting renal injuries and dying young. One of the worst things is all the comments about what they can not eat because of the diabetes. It seems that people are mixing up T1D and T2D, many people not knowing what the former is.

Most children tell others about their disease. A few, especially at secondary school, may not tell anyone. Injecting insulin may also be a problem for many, especially at secondary school. Some adolescents may inject insulin at the toilet, or wait until they get home, ending up with high blood sugar. This may be the cause of several cases of high HbA1c.

Conversation with a 25 year old Norwegian boy with diabetes

He was diagnosed with T1D when he was 14 years old, in December 2000.

After the diagnosis was made, the hospital called the boy's school and told them about the diagnosis. A nurse from the diabetes team came to his class and educated about diabetes. He told all of his friends about the diagnosis, and everyone at school knew what they should do in case of a hypoglycemic episode. It has never been an issue, whether he should tell his friends or not, and he has not experienced any negative reactions by doing so.

He has never felt any prejudices towards the diagnosis, and no restrictions were put on him, neither from the school, friends or family. He was never bullied at school because of his diabetes.

He is not afraid to tell anyone about his diagnosis, but he doesn't broadcast it either, maybe because he doesn't define himself as a diabetic. He says that the diabetes is not what he thinks is his most important feature. He studies medicine, and says that he is not afraid to get a job in the future. He has previously had a couple of jobs, but it was not naturally to tell the employer about his diabetes when he applied. It will also not be brought up in a job interview in the future, but when a job has been offered, he will tell people at his new workplace about the diabetes, so that in case something happens, people will know what to do.

When we ask him about his prospects on finding a partner, he says that he doesn't think his diabetes is what scares potential partners away, even though it has crossed his mind that a relationship with a person with diabetes might not be ideal.

He measures his blood glucose levels once a day, otherwise if he senses that he might have hypoglycemia. He uses a MDI regimen, injecting his insulin after every meal, based on an estimate of how many carbohydrates he has been eating. He is not afraid that people might see his insulin pen, and he does it whilst sitting at the lunch or dinner table with other people.

He thinks he could have controlled his diabetes and blood sugar a little better, but that he's maybe a bit too lazy, and that the benefits of a strict system might not weigh out the personal costs. He says it has nothing to do with economical costs, and that if he wanted to measure his blood glucose levels more often, the economic costs would not have been an issue.

His HbA1c has been stable at about 7.3% since the diagnosis. He was diagnosed with hypertension three years ago, otherwise he has no complications.

He says that overall he lives fine with his diabetes. He has never experienced being stigmatized or devalued because of it, even though he wouldn't mind being rid of his diabetes.

Conversation with a 23 year old Norwegian girl

She was diagnosed with T1D at the age of ten. She was then admitted to the hospital, and a diabetic nurse came to her school and educated her class about T1D. She told all her friends at school about her diagnosis and she tells us that she actually became quite popular, because she had something that made her special. Everyone at school knew what to do if she should experience unconsciousness from hypoglycemia.

To treat her diabetes she uses insulin pump, which she carries in a little purse around her neck. She tells us that she has no problem with other people seeing her infuse insulin, and that she often infuse insulin in front of other people. She says she is not afraid to get a job because of her T1D, and that she, in a job interview, tell about her diagnosis, when it seems relevant to the job. She doesn't think her diabetes will affect her possibilities to get married or find a partner in the future.

She has met some prejudice, because people think that she herself is responsible for the disease, mostly because they have read about T2D in the newspaper. She says that when she explains the difference between T1D and T2D the prejudice always disappears.

She tells us that it's somewhat harder to be a girl than a boy with the diagnosis, because girls are more self conscious, and that the disease could affect their self image and their relationship to food.

Her glucose-levels are relatively stable on an HbA1c at approximately 8 %. She has not experienced any long term complications from T1D, but she once had DKA.

Literature review

Diabetes and mental health – surveys from Norway

The first study that explored the relationship between diabetes and quality of life in Norway was Hanestad in 1992, 45% of the diabetes patients reporting that their everyday life was harder after getting diabetes (237). Several studies are later been made, the largest being the two HUNT studies from Trøndelag, which looked at people 20 years and above with different diseases, among them diabetes (both T1D and T2D together)(238).

People with diabetes (both T1D and T2D) reported poorer health, more health problems, reduced psychological well-being, higher rate of depression and anxiety than people without known disease/disability, but better than people with most other chronic diseases (239-241).

The quality of life in people with diabetes has changed during the 80's and 90's in Norway, being better in the 90's than in the 80's. The cause of this may be several; less people with diabetes are on pension or are retired, which may be seen as a positive tendency to participating in working life (242). Diabetes may also be a less stigmatizing disease in the 90's than in the 80's (243), and the care for patients with diabetes may have improved – health care professionals getting more knowledge and being able to guide their patients better. The treatment program may also have been improved, letting the patients themselves taking more responsibility, with self-care being easier with easier devices (242). It may also be explained by a reduction in additional diseases, which themselves reduce the quality of life (244).

Several studies have investigated the transition to diabetes pens and rapid-acting insulin before meals. One study from Norway reports that the patients felt they had better metabolic control, a more even blood sugar, greater flexibility being able to do things more spontaneously, feeling less guilty (e.g. when breaking the diet) and better quality of life (245). Another new device is the insulin pump, it has been studied in both T1D and T2D patients. A review of articles regarding insulin pump and T1D reported that the insulin pump had a positive impact on the quality of life, as it provided greater flexibility in lifestyle, especially with meals and socialization (165). Another study, however, reported a decrease in quality of life in children and adolescents using insulin pump (246). A third, small study reported challenges in the beginning, switching to the insulin pump, but improvement of quality of life over a longer period (247).

Adolescents have also been studied particularly. They reported poorer health than the norm, but otherwise no different from other adolescents regarding to self-esteem and mental health. The oldest, however (15-18 years) reported poorer general and mental health and poorer self esteem than the younger (11-14 years). It may thus seem that problems are occurring in the transition phase from child to adult (248).

The relationship between the youths and their family is also important. The ones who experienced much involvement and care from the parents, had a high health related quality of life (better self confidence, better mental health). Parental controlling, however, worked negatively on the quality of life (lower self-confidence, more anxiety related to the diabetes). What may be difficult is the distinction between involvement and control (248).

Mental health according to blood sugar levels

Several studies from different countries have been made to see whether good control of blood sugar betters quality of life. The results are varying, some finding that the ones with low blood sugar levels have a higher psychological well-being than those with high blood sugar, ex. (249), but many finding no such correlation, ex. (250-253). Other studies again show an inverse correlation with poorer blood sugar control leading to a feeling of better well being in some patients (254, 255).

In Norway, the HUNT studies (including both T1D and T2D) reported that people with a low blood sugar level (HbA1c < 7.5%), consistently had a lower feeling of well-being, they were less satisfied, felt less strong etc. compared to those with a higher blood glucose levels. The people with high blood sugar even had a higher feeling of well being than average (239).

In surveys among adolescents in Norway, they found a weak, but not significantly reduced quality of life among young people with high blood sugar (248). Another study among adolescents with T1D, found that the ones with the highest blood sugar levels (HbA1c 10% or above) were testing their blood sugar less often, they more often participated in organized activities and were more socially active, by the author assessed as a subjective feeling of being healthy (256).

It may be seen as a problem, if they who succeed with the treatment are less satisfied with life than those who not succeed. The ones who manage to keep their blood sugar low may be more conscientious, more obedient, but are more often experiencing hypoglycemia and are more worried. Those who are less obedient may be less strict with themselves and may feel more strong and happy (238).

Obesity and dieting – surveys from countries in the western world

Adolescents with T1D are struggling more than others maintaining their weight and are more concerned about their weight than people without diabetes (138). This might be because of the struggle to achieve the best long-term blood sugar; which might lead to incorrect dosages of insulin at some times; with low blood sugar you have to eat extra to get the blood sugar up again. This may lead to overweight (257).

People with T1D are also in higher risk of getting an eating disorder, and it is especially common in the western world (258). There are yet no studies on eating disorders and T1D with regards to culture and race (259).

One way of maintaining or losing weight among people with diabetes is not to take enough insulin, a condition known as diabulimia (260-262). A study from USA with 143 adolescents with T1D showed unhealthy weight control practice in 40% of the females and 16% of the males (263). A Canadian study following girls from 12-18 years over 4 years, showed that 38% were dieting, 45% were binge eating, 14% did insulin omission and 8% self-induced vomiting (264). In general it is estimated that 30-40% of adolescents and young adults with diabetes skip insulin to lose weight (213).

Stigma of diabetes – surveys from Norway

Few studies are found on stigma regarding T1D in Norway, and in other western countries.

In some of the studies found from the western world, diabetes is typically rated among the most socially acceptable and least severe of the illnesses (265-268). Some studies, however, from a lay population, expressed a greater desire for social distance from an individual with diabetes than from a healthy individual, suggesting that individuals with diabetes are subject to some degree of devaluation (267).

In our society it is not legitimate to assess consequences of diseases negatively, i.e. express a negative assessment of the person with the disease. We are supposed to show positive interest and empathy with the sick, and give help and support (238).

Openness and acceptance

Since diabetes is not a visible disease, some people wish to conceal or hide it, like making sure they take their medications when no one else is present. One problem with this way of living is that they may spend a lot of time being afraid to be revealed, and this may become a strain itself. If you're open about the disease you may risk the discrimination, but you may on the other hand feel safer in other ways and increase your self-esteem. It's easier to accept yourself when you're not trying to hide it. Openness has a therapeutic value itself (238).

One of the things that may suggest that Norwegians do not keep their disease secret, is that many are members of the Diabetes association; this may imply that you accept your disease and are in solidarity with other people with the same disease (238). Another fact that suggests that diabetes is getting more acceptable, is that more and more people are using insulin pumps, which are more visible for others (101).

Surveys from Norway show that publishing of the disease often it characterized by balance and ambivalence. It is right to be open but one should not force others with one's complaints. Openness is right but may also be negative, you want to be open but cannot do it completely (243).

An employer may have views whether diabetes is relevant for the work performed. Some people may experience denial of job application. Some people with diabetes will not inform about their disease when applying for a job (238).

Some people will say that having diabetes is embarrassing, in particular they do not like the attention that may appear in certain situations, often related to food that "can and cannot" be eaten (238).

Old prejudice about complications and food

One thing that seems to be a big problem for some is the common understanding that people with diabetes cannot eat the same food as "normal people". They experience for example that when eating dinner at others, they get served fruit while all the others get ice cream for dessert, because they think that people with diabetes cannot eat ice cream (235, 269).

Care and control by parents

Some parents, especially mothers, are very conscious and overprotecting, avoid giving their children food and sweets, their lunch may be offer for attention, and many feel teased. Some are prevented to do what other kids do at gym and at leisure time. It is embarrassing to ask for special treatment at school. The overprotection may be a strain for the child, even though the parents often calm down with time (243).

Adolescence

Adolescence may be the hardest time for many. Some rebel to the overprotection from their parents. It may feel important to keep the diagnosis secret and avoid all attention. It is very important to fit in. Some may deny the disease, even for themselves, cheating with insulin or eating demonstrative the same food as others, even though it may lead to problems regulating the blood sugar. Especially injecting insulin is embarrassing, many never does this while others are present. The activity area is also widened; going to parties, being up late and relate to alcohol involve testing limits for what the body can take; Some manage it well, some may have severe experiences, others again have to limit themselves and because of that feel left out. It seem that getting the disease early would ease the transition to adulthood (243).

Hypoglycemic attacks

An important cause of stigmatization of diabetes is the negative reactions from others regarding hypoglycemic episodes with loss of consciousness, which may be an unpleasant experience for others because they come without warning and is often scary, creating helplessness or confusion. Many have experienced hypoglycemic attacks at work or among strangers and they have anxiety to experience more of these attacks, mostly because of the social discomfort being observed unconscious not knowing what have happened (243).

Relationship to the partner, family and others

The relationship to a partner may be difficult. Some may think that their disease have had no impact, in other relationships care and help may be complex. Regarding relationship to others, colleges and friends, the reports are variable, some say it does not

affect this at all, others have difficulties with relations, and bad experiences may be remembered for a long time (243). We could not find any information about worries getting married or finding a spouse.

Feeling of guilt

When asked if feeling guilt, many blamed themselves (240, 241). One of the reasons for this may be their parent's reaction to their child when getting the diagnosis. Many parents think it's terrible, they may be despaired and cry a lot, making the children feeling even more guilty (238). One study found that a group participating in a group-based supervision program felt less guilt afterwards (270).

Changes with age and years of disease

The feeling of stigma and being different may change with age. When you are young, it is hard being different, and especially during adolescence you want to "fit in". When you are older you tackle the disease better, maybe partly because the older you get, more people will get chronic diseases (238).

People, who have had diabetes for several decades tell that the feeling of stigmatization has changed a lot, the problem being reduced, both due to themselves being more open, and the society becoming more tolerant (238).

Even though there exists reports about stigma and embarrassment with diabetes, it seems that most of the people with diabetes in Norway feel less stigmatized after a while, learning to accept the disease. Some report that they do not feel stigmatized at all and that the diagnosis does not affect their self-esteem, some may even say they feel more self-confident after getting the disease because they have learned to take care of themselves (243).

Stigma of Type 1 Diabetes in India

K.E.M. Hospital Pune, India

King Edward Memorial Hospital, or K.E.M. Hospital, is the largest Non-Government organization hospital in Pune District of Maharashtra State. It is serving a large population from surrounding areas. K.E.M. Hospital also runs a Rural hospital at Vadu (271).

The Diabetes Unit of the K.E.M Hospital started in 1985, offering weekly outpatients clinic. It also provide clinics for hospitalized patients with diabetes (272). It is the best referral center for diabetes patients in the region, and it is a research centre of repute. The Diabetes Unit organizes patient education for the first time in Western India, special clinics are held for children with diabetes and their parents and for pregnant women with diabetes. The Diabetes Unit is the most active unit of its kind (271). Professor C.S. Yajnik, M.D., is the Head of the Department, and he has published several studies regarding diabetes and obesity. The K.E.M. Diabetology Research Centre has a national and international reputation for its research on why Indians are more susceptible to diabetes, and have popularized the concept that the risk of diabetes and heart disease is established in the mother's womb. It is famous for describing the "thin-fat" body composition of Indians, which increases their risk of diabetes, and also the role of maternal nutrition, particularly vitamin B12 and folate (272). At present they are conducting a study on T1D, called "Characterization of type 1 diabetes patients with special reference to Growth & Body Composition", aiming to explore the features of "double diabetes" (T2D coexisting with T1D) as well as assessing reproductive growth in girls with T1D (273).

The staff in the Diabetes Unit constitutes of doctors, dietitians, educationalists and laboratory workers (own observations).

The out patient clinic has its opening hours between 9.30 and 13.30. Every weekday from Monday to Friday the clinic is open for everyone with diabetes. Every Saturday is especially for children with T1D, and pediatricians are the working doctors at the clinic (own observations). In 1995 they started outdoor camps for children with T1D (272).



Observational studies K.E.M. Hospital

When in India, we followed the daily routines at the Diabetes Unit in K.E.M. hospital.

The unit constitutes of one large waiting room filled with chairs seated by patients, with a reception desk at the entrance and a desk in one of the corners with dietitians and educationalists. Just beside the waiting room is a lab where blood samples are taken from the patients and analyzed. Further down the hallway from the waiting room you find the OPD (out patient department) offices, the doctors' offices and also a research lab.

When a patient arrives to K.E.M. for a routine check up, he will have to go through a series of steps, which will take approximately 2 hours in total.

1) Reception, "file" and payment:

Every patient has a personal "Follow-up-card", a little yellow card with the essential information about them, which they bring when they come. The card contains information about their diagnosis and that he's followed at K.E.M. Hospital, with the phone number to the hospital. It contains information such as the blood glucose level at the time of the last measurement, and also complications from their diabetes, such as stroke, retinopathy, hypertension etc. This card should follow the patient at all times in case of emergency.

When the patient comes to the Unit he delivers his "Follow up card" at the reception, and in return he will get his personal file with his complete medical history.

He pays a total of 150 rupees at the reception, 50 rupees for the consult and 100 rupees for blood samples.

There are no scheduled appointments at this Unit, the patient will just arrive at the day that fits him best, which makes Mondays and Tuesday the most busy days.

2) Laboratory:

After the patient has received his file he will go to the laboratory and measure his fasting blood glucose. After this he will eat his regular breakfast, and after an interval of $\frac{1}{2}$ - 2 hours he will take a new blood sample for the measurement of his postprandial glucose.

3) Educationalists/Dietitians:

While the patient is waiting for the analysis of his postprandial glucose, or whilst waiting for the doctor, the patient will bring his file to the educationalists, who will take the patient's anamnesis.

All the dietitians and educationalists are sitting in a row at one side of a table in the corner of the waiting room area. Several patients are seated in a row on the other side of the table, talking simultaneously to separate dietitians/educationalists.

The educationalists' responsibilities: With new patients they will take a full anamnesis following a prewritten scheme. With regular patients they will take the current anamnesis, ask for eventual complications or symptoms the patient is experiencing. They educate the patient on how to use insulin and how to use and interpret gluco-meters, lifestyle and diet. With new patients they will have a complete review of all of this, and with the regular patients they will answer any question they may have regarding their diabetes. Also they have lectures for the waiting patients on a board in the waiting room area, mostly on Mondays and Tuesdays, when the waiting room is full. All new information brought to the educationalists by the patient will be written in the patient's file, and the educationalist will look through the file and recommend when and which tests that should be taken for a complete and well-managed diabetes care. The dietitians have a diet scheme for both children and adults, where they calculate daily recommended kcal intake, based on blood glucose levels, height and weight. The dietitians also educate on and recommend exercise.

4) Doctor's office.

After measuring his blood glucose levels and the anamnesis have been taken from the educationalist, the patient will go to the doctor's office. There are several doctors working in the same room, sitting on separate desks only separated by a few meters. In the same room are the nurses.

The nurses will measure height and weight of the patient before his consultation with the doctor.










Every doctor sits with a patient. By the wall, 7-10 patients sit on chairs waiting for their turn. The door to the hallway is open, and outside you'll find more patients waiting to see the doctor. Sometimes the next patient in line will sit beside the doctor during the consultation of another patient, just waiting for his turn.

The doctor will look at the patient's file, measure blood pressure, examine specifically if the patient has any symptoms, and write a prescription of medications to the patient. The doctor will also recommend an approximate date for a new consultation. The average time for a consult is approximately 5 minutes.


5) After seeing the doctor the patient could once again go see the educationalists or a dietitian if he has any questions about his new medication.

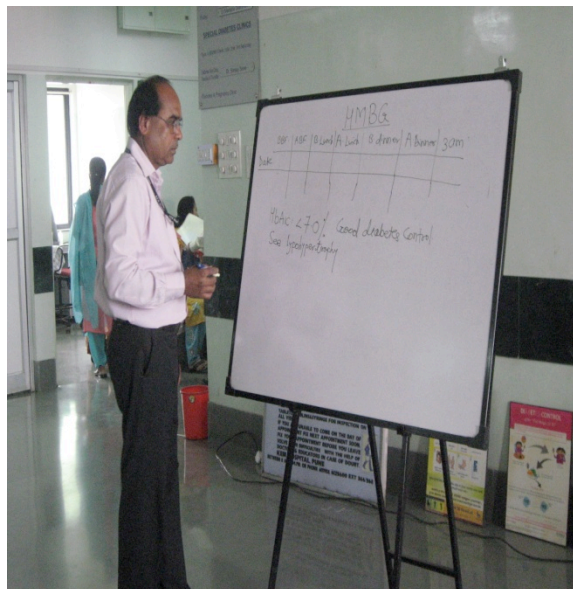
6) When the patient has gone through all this steps, he will deliver the file to the reception, and the day at the Diabetes Unit is finished

CLINIC ROUTINE FOR PATIENTS AT K.E.M. DIABETIC UNIT

TIME	ACTIVITY
8.00 TO 9.00 AM	 1. RECEPTION REGISTRATION & PAYMENT
8.00 TO 9.00 AM	 2. LABORATORY FASTING SUGAR & OTHER TESTS
8.00 TO 9.00 AM	 3. MEDICATION (BEFORE BREAKFAST) INSULIN & or TABLET BEFORE BREAKFAST
8.30-9.30 AM	 4. CLINICAL EXAMINATION • WEIGHT • BLOOD PRESSURE • COMPLAINTS • EYE CHECK UP
8.30 -10 AM	 5. BREAK FAST
8.30 -10. AM	 6. SCREENING
10.00-11.00AM	 7 LECTURE
10.00-11 00AM	 8. LABORATORY POST PRANDIAL SUGAR (1.30-2.00hrs.after breakfast)
11.00-01 00 PM	 9. CONSULTATION

NOTE:
PLEASE BRING FOLLOWUP CARD,NEEDLES,
TABLETS, INSULINS&SYRINGE FOR INSPECTION ON
ALL VISITS
IF YOU ARE UNABLE TO COME ON THE DAY OF
APPOINTMENT FIX NEXT APPOINTMENT SOON.
FIX YOUR APPOINTMENT BEFORE YOU LEAVE
SOLVE YOUR DIFFICULTIES WITH THE HELP OF
DOCTORS & EDUCATORS IN CASE OF DOUBT.
KEM HOSPITAL, PUNE
BETWEEN 8 AM TO4.PM. OR PHONE :6111958. 6125600 EXT 366/368





A routine check up thus costs 150 Indian rupee (INR), and consists of measurements of blood glucose levels, both fasting and postprandial, blood pressure, height and weight. The patients have a short amount of time with the doctor, but could have substantial amount of time with an educationalists who could answer their questions. The yearly follow up consist of HbA1c, examination of the fundus, measurement of standard blood parameters, triglycerides and cholesterol, EKG, and filament examination of the feet for detection of neuropathy. The patient will have to pay for each test taken, and this will add up to a large sum for an Indian inhabitant. For example, the HbA1c costs INR 300. All tests are thus not always taken.

As a comparison, the per capita income in India was in 2009-2010, INR 46 492 a year, making the monthly income INR 3900 and the daily income INR 127 (85).

K.E.M. Hospital operates with special clinics for children with T1D every Saturday. Pediatricians are having the consultations. When the patients are waiting for the consultation a coach is playing ball with the children in the waiting room. K.E.M. arranges different activities with the children with diabetes and their parents, such as camps, trips to water parks, picnics and playgroups. They also arrange education for the parents. Dr. Kalpana, a pediatrician at the Diabetes Unit, explains the problems these families are facing. A lot of parents measure the blood sugar levels of their children, but without really understanding the true meaning of the values that appears, which makes it difficult to well manage and fully regulate the diabetes of their children. The glucose measuring strips are also expensive, with a price of INR 22 each, a reason why the blood glucose levels are not measured as often as they should be. HbA1c, with a price of INR 300, is neither not measured as often as it should be. She explains how diabetes is a social issue for the children with diabetes and their families. For a child with diabetes it is difficult to get married, the family won't tell people about the disease, the disease is

kept hidden at school and at work, and restrictions are put on to the child from the school and also sometimes from the parents. She also says it's an economical issue; the patients can't afford all the necessary tests or the appropriate treatment. Education is a big problem. When not everyone is aware of that T1D exists in children, that might be one reason why it's not always discovered, and often people don't fully understand the effects and necessity of treatment.

We observed that a lot of the children with diabetes were growth retarded, some severely. We also met young children with eye complications, foot ulcers and hypertension. Complications are common due to economic issues – treatment is expensive, and the, often poor, parents have to pay it themselves. Another problem is that many of the patients live in rural areas, quite far away from the hospital. The parents are not getting sick days, and it is often a long and expensive way to get to the hospital, which means many of the children are not getting as frequent check-ups as they should, resulting in poorer control of blood glucose and more complications. This is even more common with girls than with boys.

Stigma is also a problem, as the parents do not want to tell school and friends about their child having diabetes, since having diabetes is a huge stigma in India. This also produces a great risk to the child if getting hypo- or hyperglycemic and their teachers and friends not knowing what is happening and what to do. K.E.M. Hospital is doing a great job trying to convince the parents that telling school and friends is necessary to keep their children as safe as possible, they also offer school information – going to the schools and informing teachers and students about diabetes and how to handle the situation children with diabetes can get into.

In India the diagnosis T1D has other consequences than in Norway. It is often a huge strain for poor families, since all treatment basically have to be paid themselves. This often leads to suboptimal treatment and complications occur to a high degree. In addition the parents often have no opportunity to follow the children to the controls. Some children have to travel long way by themselves, others are not coming to the controls at all.

Equipment is also limited. Insulin pumps rarely exist, since no one can afford it.

There are, however, arrangements for the poorest families. Pharmaceutical companies have arrangements that finances a part of the equipment for those with the least money, this is administrated by the hospitals, that decides who are participating. The hospitals are also doing the best they can with the resources they have available, and they encourage the families to treat their children as good as they can, and states the importance of the regularly controls.

Most of the patients tested their HbA1c less than once a year. We met young girls with diabetic foot ulcers, growth retardation, underweight and hypertension, and we met some girls that were admitted with diabetic coma. Also, some boys we met were showing the same tendency.

We also participated in a diabetes conference for all doctors in the area, and there, surprisingly few doctors knew that blood glucose should be measured several times daily in T1D patients.

Conversation with a 22 year old female patient at K.E.M. Hospital:

She was diagnosed with T1D mellitus at the age of 7 years. At the time of diagnosis she had fever from an infection, and polyuria. When she got the diagnosis few people understood what this was, because not many people have T1D in India. First, she went to a local hospital only to get misdiagnosed. Only after a few months, after she came to K.E.M Hospital in Pune, she got the right diagnosis – T1D. At K.E.M. Hospital she received help to learn how to manage her diabetes and blood glucose, with insulin, exercise and diet.

Now she comes once a month to measure her pre-and postprandial glucose, blood pressure, weight and height. Every third month she tests her HbA1c, and she has an annual check-up with monofilament test, fundus check, and microalbuminuria.

She tells us about the difficulties of having T1D in India. At the K.E.M. Hospital they have a saying: Tell people that you suffer from T1D mellitus! She says that despite this it's typical for people to hide the fact that they have diabetes from teachers, other pupils, friends, coworkers and employers, because of a huge stigma connected to the disease. When she went to school, she couldn't tell anyone about her disease, and she heard stories about children who died from hypoglycemia at school, because no one knew that the treatment was simply sugar. Now she works at an IT-company, where she keeps it hidden that she suffers from T1D. She tells us that this is because she wouldn't have gotten the job if she told that she had the diagnosis.

Economical difficulties; She has to pay for her check-ups, insulin, syringes, needles, blood glucose tests and HbA1c. Her monthly check-ups cost INR 300 and her third month check-ups cost INR 1360. She suffered from hypertension at the age of 12, and diabetic retinopathy at the age of 21. She had to pay herself for the laser operation, which costs 16000 rupees. She spends INR 1600 a month on syringes, and approximately INR 300-400 on blood pressure medicaments. She measures her blood glucose 3 times a day, and each test costs INR 22. HbA1c costs INR 300.

She has a job, and comes from a city in the western region in India. She tells us that she has been lucky, not many people are able to pay the costs of having T1D. She feels well taken care of at the K.E.M Hospital.

She tells us that it will be difficult for her to find a husband, because she is not "marriage material". It's hard for her parents to find a husband for her because of her disease. She tells us that this is also difficult for boys with diabetes.

Despite this, she tells us that she is quite happy with her life, she has good job, and earn enough money to pay for the costs related to her diabetes. The fact that she will not get married is also something she has learned to deal with and accept, and because of the job, getting a husband is not "necessary".

This girl is one of the well-managed patients we met at the K.E.M. Hospital.

Literature review

Despite the fact that T1D is more common in girls than in boys in most regions of the world, and that there has been reported a female excess of T1D in populations of Asian origin since the 1970s, certain endocrine centers in northern India report a higher outpatient attendance of men and boys with T1D. Generally diabetes is diagnosed earlier in Indian boys than in girls. The boys are less likely to develop DKA, they have a better chance of reaching specialist centre and a better chance to receive appropriate treatment and regular follow up. The boys also appear to be more willing to follow intensive insulin therapy (91).

The girls in India are missing from the clinics (274). We would like to look at the factors behind this phenomenon, that is, the gender-related social and cultural issues that has lead to the disproportionate burden of diabetes on young women in India (91).

Social and lifestyle factors

T1D poses a major burden of care to the family members, especially parents, due to its early age of onset, sometimes diagnosed as early as infancy. The parents are not only involved in bringing the children and adolescents to the hospital for consultation, but are also involved in administration of insulin and overall management. All this has impact on daily functioning and management. "In fact – T1D is considered as a family enterprise rather than individual's responsibility" (275).

Being a chronic illness, T1D is also associated with a lot of stigma in India (275). T1D is considered a social stigma (91) and the stigma related to diabetes is particularly more pronounced for girls (276). In addition, parents also experience substantial anxiety, shame, grief, guilt and financial hardships (275).

"T1D is considered a social stigma for girls; many parents try to hide their daughter's condition from teachers, friends and relatives. Often, the effectiveness of insulin therapy is compromised by a lack of support from family members and the community, coupled with anxiety or feelings of guilt relating to having diabetes" (91).

The parent's anxiety coupled with the stigma can be exemplified with an article written at medindia.net for the world diabetes day 2008, that begins with "Who will marry my daughter who has diabetes? asks Ram Anuj, a native from the Northern Indian District of Uttar Pradesh" (276).

"Another problem among the girls due to the prevailing socioeconomic problems, the parents find it difficult to arrange their marriages, and being a diabetic is a stigma for them" (277).

Stigma is particularly complex as it operates at many different levels and has both social and psychological aspects. Also there are many factors surrounding stigma including denial, shame, blame, fear, rejection and discrimination. Diabetes-related stigma at the workplace or in the community and self-stigma has adverse impact on the mental health and feeling of wellness of people with diabetes in India. Dealing with a chronic illness such as diabetes cause emotional and behavioral challenges, at times, leading to depression. "For any child or adolescent living with diabetes, learning to cope with it is often a daunting task" (276)

Inferior care

Diabetes-related stigma is particularly severe as diabetes is a life-threatening chronic condition (276).

From a global perspective, lack of insulin is the commonest cause of death in a child with diabetes. People in poor countries must buy their own insulin, and its cost at the counter – often well above the price paid to the manufacturer – can become a matter of life and death. Families must make a choice between insulin for one child or starvation of the rest. The consequence, in parts of India – which has more people with diabetes than any country in the world – is that girls are missing from the clinics. Syringes and needles must also be paid for, as must tests for glucose in the blood or urine (274). People at large, in India, are not medically insured and have to buy insulin injections, syringes and other accessories required for treatment (277). For example, in Chennai, India, people from middle- or low-income groups can spend a sixth to a quarter of their income on diabetes care (278). Poor families find it difficult to commit a quarter of their monthly income for the medicine and healthcare required by a diabetic child. Debilitating, social, cultural and economic factors continue to discriminate against women and girls in appalling ways (277). Indian girls more often develop DKA because their insulin dose is stopped or reduced by parents wanting to reduce the cost of treatment. “Many parents perceive a girl with diabetes as a burden, difficult to marry off, unable to have children, and best “disposed off”. This is common even among many educated families.” (91).

Insulin has a price and in a low-income country as India, this will affect the course of treatment and the course of the disease of the children with diabetes. Also syringes, needles and tests for glucose cost money and must be paid for.

“Women with the condition are worthless in a still male-dominated society, considered to be a financial burden” (91).

The failing treatment of the diabetic girls in India leads to severe effects. These diabetic girls experience increased morbidity, premature long-term complications of diabetes and death because of lack of insulin. They have problems like recurrent DKA, diabetic coma, soft tissue infections (abscess), chest tuberculosis and growth retardation, which is mainly due to intermittent stopping of insulin, “under-dosing” because of economic constraints and once a day insulin only. These problems lead to a drop in school attendance. Also they prematurely develop microangiopathic complications like retinopathy, nephropathy and neuropathy, because of their uncontrolled diabetes (277).

The “missing girls” are especially evident in regions in northern India (91).

Data from a two-year outpatient registry at Bharti Hospital, Karnal, in Haryana state of north India, reveal striking findings. Nearly twice as many men under 30 years old were diagnosed with diabetes compared with women in the same age group. In the age group 0-14 years, the gender ratio is one to one. But in young people aged between 15 and 30, it drops surprisingly: For every 100 boys with diabetes attending the outpatient clinic, 54 girls with the condition are somehow lost during follow-up. Similar data are reported in many other diabetes centers across northern India, including Amritsar and Gwalior. However, this situation seems to be confined to a few states; the more educationally advanced regions of the country, such as New Delhi and Karnataka, do not report such trends (91).

In India, there is an urgent need to educate parents and their children regarding their diabetes, possible complications and their remedies. There is still a tendency to switch over to alternative medicine and stop insulin (277).

“Diabetes-related stigma can block access to existing diabetes-care services. If people with diabetes are feeling sick, then many mainstream systems do not want to spend their scarce resources on them, when they are fighting to have enough antibiotics and IV fluids to combat infections and diarrhea, still the leading causes of death in children in the developing world. There are not enough specialists in many regions who are knowledgeable about diabetes to take care of all the children”, said Mr. Phil Riley, Campaign Director, World Diabetes Day Campaign (276).

In addition, lack of skilled healthcare staff, apart from the diabetes physician, exacerbates the situation. As already mentioned, dealing with diabetes may cause emotional and behavioral challenges, and at times, lead to depression. There is need for high-quality counseling sessions at the diabetes care and treatment centers, for people with diabetes and their family members, which may eventually help combat stigma. It may also help them to adjust to the lifestyle changes needed to stay healthy. But, there are not enough nurse educators, diabetes counselors, nutritionists, podiatrists, or other health educators to help raise awareness and understanding of unique care and treatment needs of people with diabetes in society. This not only fuels the diabetes-related stigma, but also reduces the quality of healthcare for people with diabetes. “The patient’s inability/unwillingness to pay for this additional support also hinders the treatment” says Dr Surendra Khanna, a Physician at Diabetes centre in Kanpur (276).

The treatment for diabetes cost money, and in addition to that it put a strain on the family. Combined with the stigma that follows the disease and the general preference for male offspring, this leads to the failing treatment of diabetic girls in India.

The DREAM (diabetes research and management)-trust was formed in 1995 by Dr. Sharad Pendsey and his wife Swati as a response to the failing insulin treatment of girls in India, after the shocking incidence of deaths of two girls because of lacking insulin. Parents of these girls had stopped giving insulin as they could simply not afford it any longer (277).

The main object of this trust is to help poor children with diabetes. That is, to offer a complete healthcare to the type 1 insulin dependent, underprivileged people with diabetes, especially children and with a particular focus on females. They prioritize girls, because of the discrimination against them. The trust has so far sponsored about 600 children with T1D, who are given free insulin, syringes, monitoring strips and glucometers and their health is monitored. The trust has goals to ensure survival of the children with diabetes, reduce morbidity, prevent long-term complications, rehabilitate and to create better awareness and education of children and their parents. All of this to help the children escape a cycle of poverty. They are a philanthropic organization, which relies on people donating funds. It is also financed through Dr. Sharad Pendseys private T2D clinic (277).

Poor communication

Urogenital issues are common in young women with diabetes, but lack of privacy, social taboos regarding urogenital issues and a comparative lack of qualified female diabetes specialists coincide to exacerbate the under-recognition of these urogenital infections. In many cases, girls find it difficult to discuss menstrual disturbances, premenstrual

syndrome or contraception with male diabetes healthcare providers, and may also neglect to call attention to important factors in their medical history (91).

Culinary cruelty

Overall, the per capita calorie consumption of girls is significantly lower than boys. While occasional fasting is an integral and accepted part of many religions, women seem to undergo more than their fair share of fasts. Especially North Indian girls fast at regular intervals in order to pray for, say, a good husband or a male child (91).

Less physical activity

According to traditional gender-specific roles, girls should remain indoor, perform domestic chores, (277) and avoid outdoor activities or sports. Moreover, archaic social norms prevent girls from going unaccompanied to public places, and the lack of gender-neutral parks or sport-clubs deters girls from pursuing structured physical activity programs (91).

Mental health

In Pubmed, Google and Cochrane no relevant search results appeared when trying to find articles about T1D and well-being or mental health in India.

Discussion

T1D is a chronic, concealable disease, which needs careful and lifelong treatment to prevent complications and death. When the treatment is failing, T1D can be converted into a visible disease, because of a visible physical deformity, such as foot ulcers, amputations or growth retardation. Also the necessity of regular insulin infusion can make this a disease difficult to conceal, as can hypoglycemia. As described, chronic, visible and concealable diseases can all carry with them stigma, that is, they can all be a “mark of disgrace” that spoils normal identity. Also the reliance on medical treatment is a stigmatizing attribute of T1D. Hence, T1D can be characterized as a stigmatizing identity. The stigma associated with the disease can then lead to reduced healthcare seeking, inequitable treatment, reduced psychological well-being and physical health. Also, the associative stigma attached to the disease can render the family members and friends of a person with diabetes to feel equally stigmatized. The subjects with T1D may also suffer from labeling, stereotyping and devaluation from the society. Shame, fear and guilt may also follow the stigma. In the society today, where we are measured against the goal of perfection, T1D could be viewed as a deviance – an imperfection – and thus leave the individual with diabetes vulnerable to devaluation and enacted stigma.

In spite of this possible stigma attached to T1D, T1D nor diabetes mellitus as a whole is not normally listed as a classical stigmatized identity, opposed to that of HIV/AIDS, mental illness, leprosy and epilepsy. This is also apparent when very few relevant search results appears as you type “stigma AND diabetes mellitus” in to PubMed, Google or Cochrane. This could be the result of that little or no stigma is attached to T1D, at least not in the countries distributing articles into these search engines. But when we searched for articles about stigma of diabetes in India, the number of articles was overwhelming. The stigma that attaches to any condition is socially constructed, and therefore it varies from setting to setting, and different types of identities are culturally devalued to different degrees. We hypothesized that the stigma attached to T1D was greater in India than in the western world, and the lack of articles describing stigma in T1D and diabetes mellitus in Norway/western world in compare to those describing stigma in diabetes and T1D in India, supported our hypothesis. But, we can't overlook that this may also have to do with a different focus on the stigmatizing process of T1D between the two. Thus, we looked at what consequences T1D brought to the individuals living in Norway in comparison to those living in India, to see if that could bring us closer to an answer.

There is no doubt that there is a care crisis for girls and young women living with T1D in India. They often experience diabetic complications; they develop long term complications in early age, such as nephropathy, neuropathy and retinopathy, as seen from the K.E.M. Hospital. Also the mean age of death in an Indian study showed to be 27 years old for female patients with T1D. They have problems getting married and to get a job, unless they keep their condition hidden. They are afraid to tell people at school or friends about their disease. Their parents also try to keep their condition hidden from teachers, friends and relatives. All of this is also seen in boys, perhaps to a lesser extent as for the girls, as the mean age of death for all patients with T1D was 29 years, indicating that the males are dying at a higher age, making the mean age of death higher than 27. This necessity to hide the condition in the Indian society is an indication that

there is attached a cultural stigma to T1D in India. The fear of telling shows that there is felt stigma associated with T1D, as well as associative stigma in family members. The enacted stigma shows when they tell about the disease and this leads to a difficulty of getting a job or to marry someone. Hence, subjects with T1D in India experience cultural, felt, enacted and associative stigma.

In comparison, in Norway, late complications, like nephropathy, retinopathy and neuropathy, are uncommonly seen in children and adolescents. The numbers of acute complications are also low, with about 5 % a year who experience DKA. The people with T1D are not very worried about getting a job or a spouse, even if their disease were to be revealed, as seen in interviews with subjects with T1D. Also, most children tell others about their disease. This could be an indication that there is a minimal amount of cultural stigma attached to T1D in Norway, as well as the felt stigma is minimal. In some studies from the western world, diabetes is typically rated among the most socially acceptable and least severe of the illnesses. But, even though the patients in Norway with T1D are not facing the same problems with finding a spouse or job, and the management of diabetes seems to be good, T1D is not entirely stigma free. Some people with T1D report that they do not want to inform about their disease when applying for a job, indicating that there is felt stigma associated with T1D in Norway. Another example of felt stigma and passing are the children with T1D who infuse their insulin at the toilet at school, and in this way try to “pass as normal”. Other people with diabetes have experienced some problems regarding relationships with others, indicating that there is some cultural and enacted stigma attached to the disease. Some people report prejudice towards the people with T1D, because people think that the patients themselves are responsible for getting it. This is often due to articles about T2D and diets in the newspapers, and that some people do not know the difference between T1D and T2D. Also, some studies from the western world have shown that people have expressed a greater desire for social distance from an individual with diabetes than from a healthy individual, suggesting that individuals with diabetes are subjects to some degree of devaluation and enacted stigma. When talking to health care workers working with diabetes in Norway, they say that many children feel stigmatized and different. Hence, there are evidences of cultural, felt and enacted stigma in Norway, as well as prejudice, but not to the same extent as in India.

But why are the cultural stigmas so different in these two countries? This could have many answers. The prevalence of T1D differs enormously between the two, as Norway has one of the highest prevalence of T1D in the world; India's prevalence of T1D is low, especially compared to that of T2D. Maybe people in Norway know more about the disease, and in that way this removes “the mystery” revolving the disease, and this could lessen the cultural stigma. Both in Norway and India the people with T1D are encouraged from health professionals to tell people that they suffer from the disease, so that people in their surroundings will understand the need for constant insulin infusions and know what to do in case of a possible hypoglycemic episode. In Norway, a diabetic nurse comes to school and educates pupils and teachers about T1D when a child in their class has been diagnosed. Also, the hospital calls the school and explains why one pupil is missing from school, when the patient is admitted. To inform and educate people about T1D is a way to raise awareness and reduce the mystery revolving the diagnosis; and in that way reduce stigma. People who have had diabetes in Norway for several decades tell that the feeling of stigmatization has changed a lot, the problem being reduced, both due to themselves being more open, and the society becoming more

tolerant. In India, however, the telling is solely left to the person with T1D. To leave this up to the patient itself, who may not possess the same knowledge about T1D as a diabetic nurse, and also suffers from felt stigma, could make the process of disclosure even harder for the Indian patients.

Another possible answer could be that the rate of complications is lower in Norway compared to that in India. The disease could then be viewed as more dangerous in India, and in that way, more stigmatizing attaches.

The problems in India are not only related to stigma of T1D. As we can see, to be born a girl in India is in general, not easy, where the woman can in fact be seen as less worthy than the man. To have a daughter can pose problems for the parents, as they have to marry her off with a dowry. This indicates that only to possess a female gender is to possess a stigmatizing identity in India. But the fact that T1D is something that you have to hide, because this will make you less attractive as a spouse or for a job, is an indication that T1D is an additional stigma for the girls. T1D gives an additional loss in status, which is considered a component of stigma. Norway is considered one of the most gender equal countries in the world. When comparing the two countries, Norway has a gender inequality index of 0.075, whilst in India it is 0.617 (0 being best possible, 1 being poorest possible), which tells us there's a much higher gender inequality in disfavor of the female gender in India. At Elverum Hospital a few more boys are followed up than girls, but this matches the number diagnosed, where a few more boys are diagnosed than girls in Norway. This indicates that there is not a problem of missing girls with T1D from the clinics in Norway. However, the girls in Norway may experience somewhat more difficulties related to the disease, than the boys, in terms of self-image and their relationship to food.

Also, the economic issue can attribute to the outcome of the missing girls, and some boys, from the clinics in India. The treatment of T1D is expensive for an average Indian family, and this could in itself lead to the poor treatment of T1D in the young patients, which again can lead to higher rates of complications amongst the young patients. Because of the general stigma attached to the female gender, the girls seem to be chosen away when the Indian families are deciding whom to treat. This results in fewer girls attending the clinics than boys, even though the prevalence of T1D is suspected to be higher in girls. In Norway, the relative mean income is much higher than in India, and with the National Insurance Scheme the expenses are kept low on treatment. In India they spend on average a quarter of their income on treatment, whilst in Norway, the exemption card makes the treatment costs to be approximately 0.5 % of the mean income in Norway.

The differences in complication rate between the two countries may also stem from different treatment regimens. In Norway almost everyone is on intensive treatment, 57 % of the patients with T1D use insulin pumps, the rest are on MDI, only very few are on conventional therapy with two injections a day. Also new and more expensive insulin analogues are being used. In India, most patients with T1D are on conventional therapy with two injections a day, they use syringes, and also the bovine insulin is widely used, because of its lower costs compared to the human analogues. This again has to do with an economical issue; the insulin pump is extremely expensive for the Indian people, and as described, the bovine insulin is cheaper than the human analogues.

The difference between India and Norway seems to be huge regarding the stigma associated with T1D. Even so, Norway is not stigma free and all the problems regarding

T1D in India are not solely attached to the stigma of the disease in itself. As mentioned above, stigma can lead to reduced healthcare seeking, inequitable treatment and reduced mental and physical health. We need to find ways to reduce the stigma of T1D, especially since this is a disease that appears early in life and that could lead to severe complications and death if not treated properly. We propose that to reduce the existing stigma we need more studies exploring the stigma attached to this disease, to get a clearer view of its extent and causes. Educating the general population about T1D is one way to reduce the stigma, by raising the awareness. It's important to continue to encourage the patients to disclose their diagnosis to their friends and family, even if that puts them in a possible situation of enacted stigma. Openness has a therapeutic value in itself and it will be easier to accept yourself when you're not trying to hide it. Also, this could reduce the felt stigma attached to the disease. It's important for healthcare staff to be aware of the stigma attached to T1D, so that they can be attentive to its possible consequences in their patients. There is need for skilled healthcare staff that can provide a holistic rather than biomedical approach to the patients, that is, to accept the patients as decision makers, and allow the patients to talk about what they find important, rather than just treating the diagnosis. In that way we could help reduce the shame, fear and guilt and also raise the self-esteem and life chances of the people with T1D.

Conclusion

The feeling of stigma is a part of having diabetes. The consequences, however, vary largely in different parts of the world. The feeling of being stigmatized largely affect the treatment of the child with diabetes, which in turn affects the risk of both short term and long term complications. Because of the possible serious consequences of diabetes complications, it is important to increase the general knowledge about diabetes, and thus try to reduce the stigma as much as possible.

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