Changing Diabetes Care for Good

How everyone stands to benefit from a better understanding and use of patients' perspectives and experiences of life with type 2 diabetes when designing and implementing treatment interventions.

MIKKEL BROK-KRISTENSEN
ReD Associates

The current approach to diabetes management is flawed. Providers' use of the concepts of self-management and compliance disguises a system in which the perceptions and everyday life of the individual patient is discredited and disregarded. The result is the loss of both patients' life quality and the wasting of billions of reimbursers' dollars. This paper proposes a new direction in which providers move to change practice and acknowledge the equal importance of patients' non-biomedical perception of diabetes in regards to cause, etiology and treatment initiatives. The paper argues that this change can potentially lead to a great improvement in the life expectancy and life quality of people with diabetes. It presents the outline of a practical model intended to assist providers in taking the first steps towards this crucial evolution in practice.[1]

INTRODUCTION

Diabetes care is big business. This year alone, the total expenditure on diabetes and its complications will total more than 236 billions USD.[2] Similarly, the world market for insulin alone – prescribed for people with no or very limited self-production of insulin - is expected to be worth well over 11.8 billions USD in 2010 (Gale 2006: 1267). Regrettably not all of this money is well spent – in fact billions are wasted. Too many interventions are inadequately designed and executed, resulting in a poor efficiency of both public and private health care reimbursers' spending.

To make matters worse the number of people with diabetes is increasing at a phenomenal rate. In 2030 more than 30 million Americans will have to live with diabetes, an increase from 17,702,000 Americans in 2000 (WHO estimate).[3] The increase will almost

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[1] I would like to thank Brinda Dalal for constructive critics of previous versions of this paper and my colleagues at ReD Associates with whom the presented understandings have been developed.

[2] The human, social and economic impact of diabetes. The International Diabetes Federation http://www.idf.org/home/index.cfm?node=41 , accessed the 27th of August 2007

[3] World Health Organisation, http://www.who.int/diabetes/facts/world_figures/en/index3.html , accessed the 14th of July, 2007

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exclusively be seen in the rising number of people with type 2 diabetes – also known as adult onset diabetes.[4] Type 2 diabetes, which is the focus of this paper, already accounts for approximately 90% of all cases of diabetes and is largely the result of physical inactivity and excessive body weight (WHO)[5]. It is not only the 'fat Americans', as the European media so often depicts America, that are fighting a Sisyphus battle against diabetes. Diabetes is on the rise in every single country in the world, and by 2030 the global number of people living with diabetes is estimated to reach an astonishing 366.000.000 people – making it a 'global diabetes epidemic' (WHO).[6]

The economic burden of diabetes is vast even today. In the US a 1997 study showed that 10% of the total cost of health care was on diabetes and 25% of all Medicare payments where made to people with diabetes (Björk *et al.* 2000: 22). Improving the efficiency of intervention is critical if we want to ensure that the growing economic burden of caring for diabetes and its complications will not cause the health care sector to collapse.

However, of prime concern are the individuals living with diabetes that carry the burden. Diabetes is a chronic disease that occurs when the pancreas does not produce enough of the hormone insulin, or, alternatively, when the body cannot effectively use the produced insulin, hereby affecting the blood sugar levels that are controlled by insulin. An uncontrolled blood sugar level can either lead to raised levels of blood sugar (hyperglycemia) or lowered levels (hypoglycemia). This in turn can lead to a number of serious medical conditions. Diabetes is the leading cause of non-traumatic amputations and new cases of blindness in adults; it dramatically increases the risk of stroke; high blood pressure; central nervous system diseases; periodontal disease and depression (Center for Disease Control: 2002; WHO).[7] It goes without saying that this is a serious challenge to people's quality of life and studies show that their life expectancy – often referred to as 'life quantity' – is cut by 10-15 years, even when treated (Björk *et al.* 2000: 22).

Encouragingly much can be done to minimize complications, but the paradox, according to providers, is that these measures are not being implemented to anywhere near the extent to which they could be. With strong scientific evidence backing this assertion and progress being in the interest of both patients, providers, reimburses and society at large the

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[4] Type 2 diabetes typically affects middle-aged or older individuals and occurs when the pancreas does not produce enough insulin or when the body fails to use produce insulin effectively. Approximately 90-95 % of the diabetic population has type 2 diabetes, the remainder live with type 1 diabetes. Type 1 diabetes typically occurs in children and adolescents and affects them for their entire life. It occurs when the pancreas fails to produce insulin. (Prevalence of diabetes. The International Diabetes Federation) http://www.idf.org/home/index.cfm?node=264 , accessed the 27th of August 2005

[5] http://www.who.int/mediacentre/factsheets/fs312/en/index.html , accessed the 14 July, 2007

[6] http://www.who.int/diabetes/facts/world_figures/en/index3.html , accessed the 14 July, 2007

[7] To exemplify the severity about 50% of all people with diabetes will be affected by damages to the nerves. 10-20% will die of kidney failure. 50% will die of cardiovascular disease. WHO Facts http://www.who.int/mediacentre/factsheets/fs312/en/index.html , accessed the 14 July, 2007

natural question then is to ask: What is the problem? – Why is the prevalence of complications not decreasing?'.[8] Attempting to address this apparent paradox has brought about an increased interest in the psycho-social aspects of how people live with diabetes (Schoenberg *et al.* 2005). It has also been the focus of several projects that I, and the company I work for, have been engaged in over the past 2 1/2 years. It is data and findings from these projects on type 2 diabetes that serve as the foundation of this paper.

SELF-MANAGEMENT

The proliferation of oral and injectable therapies has essentially placed the responsibility for achieving good control of diabetes on the person living with diabetes: Good control is defined as maintaining the right level of blood glucose (International Diabetes Federation).[9] This means the responsibility for both medical and non-medical treatment initiatives (i.e. dieting and exercising) lies in the private space of the person with diabetes. The health care system and its different actors have thereby become suppliers of products, services, information, guidance and evaluation to the patients, with providers prescribing medication and giving advice and directions on diet, exercise, stress management all for the patient to self-manage. To use the words of a nurse we interviewed in a project: *"We don't want to take over their diabetes, we want them to manage their own diabetes. We want to be the people that they can come to for advice"*.

Providers and other actors within the health systems view this concept of self-management in an un-critical light, but deeper scrutiny is required if we are to understand the real impact of the concept. Rose (1992), highly influenced by the thinking of Michel Foucault, explicates that the modern understanding of the self, is indeed what could be labeled an enterprising self: *"The enterprising self is [..] a self that calculates about itself and that works upon itself in order to better itself"* (Rose 1992: 146). Foucault in his study of Greek and Roman philosophy has showed how working upon yourself with self-analysis and confession was considered integral to taking care of yourself, making management of the self an old western tradition (Foucault 1988; Samuelsen and Steffen 2004).

The life of the enterprising self is thus a continuous flow of situations in which it is attempting to choose what best serves its interests and self-improvement. It is through these choices that the enterprising self is at once creating and defining itself in the eyes of others and itself: *"The self is to style its life through acts of choice."* (Rose 1992: 151). The concept of the enterprising self hereby shows just how intrinsic choice-making is in our, western, understanding of what constitutes the individual as an acting subject (Foucault 1998, 2000;

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[8] According to the International Diabetes Federation (IDF) a 1% reduction in HbA1c – the measure for long term average level of blood glucose called glycohemoglobin, which is largely agreed to be ideal around 6.5 % < HbA1c - reduces diabetes-related deaths by 21%, risk of micro vascular complications by 37% and myocardial infarction by 14%. http://www.idf.org/webdata/docs/Fact_sheets.pdf , accessed 15 July, 2007

[9] http://www.idf.org/webdata/docs/Fact_sheets.pdf , accessed 12 July, 2007

Rose 1992). It is because of this strong emphasis on the individual as an acting subject, that self-management is perceived as a self evident process whereby the individual living with diabetes will inevitably make decisions and take actions regarding treatment of diabetes that serves their own interest. Together with the assumption that treatment behaviour is a direct result of patients' decision making this is an important part of providers' perspectives on diabetes treatment (Hunt and Arar 2001: 348).

PROVIDERS' AND PATIENTS' DIFFERENT PERSPECTIVES ON DIABETES

Patients are generally taking it upon themselves to manage their diabetes. Equipped with medication, information and advice from providers on topics such as diet and exercise, they endeavor to find additional information and tools from the Internet, other patients and people within their social network (i.e. family, friends, the local minister etc.), hereby adding to the pool of what they consider relevant treatment initiatives. Patients generally consider more options than providers including such diverse initiatives as yoga, prayers, herbal tea and other medical options beyond those prescribed by their providers.

That patients and providers have different perspectives on diabetes is well-established (i.e. Balshem 1993; Mattingly 1998; Schoenberg *et al*. 2005; Hunt and Arar 2005). I will therefore only give a few examples from one in a series of the projects we, in the company I work for, have conducted on type 2 diabetes. The project that took place in greater London involved twelve people living with type 2 diabetes, who we observed in their homes, with and without their families, at their jobs, shopping, picking up the kids from school and doing the many other things that 'the everyday' is comprised of.

Cause explanation – understanding the cause of my diabetes

We found that people have considerable knowledge of the medically accepted causes of diabetes, such as obesity, unhealthy diet and a sedentary lifestyle, but nevertheless most of the people we met in this and other studies have their own individual 'cause explanation'. It is in these you find the difference between patients' and providers' notions of causality. We have found that while some people will refer to one of the medically accepted causes, they simultaneously explain how they also believe other causes, that do not find support from the medical establishment, were important triggers of their diabetes. Some patients exclusively attribute their diabetes to such causes. One patient, a man in his late fifties, explained how he got diabetes from eating large quantities of mango over the course of a summer.

> Interviewer: So what caused your diabetes?

> Informant: About seven years ago I got a big box of mango. So I was eating mango like nobodies business [...]. I was going to the toilet many times, so I went to the doctor and the nurse, she tested my bloodsugar. And I was very high. And she was crazy; she said that I was going to die. [...]. And she said straight away that it was diabetes.

In this and other studies we have encountered a vast array of cause explanations, their common trait being that all gave valuable insight into to how that person was living with diabetes, showing how ideas about the past and the present were influencing the patient's understanding. They simultaneously manifested the uniqueness of their specific diabetic condition (Ferzacca 2000: 39). From a provider perspective, this serves to highlight the importance of listening to peoples' cause explanations in order to understand their perspectives on diabetes, the key suggestion in the 'narrative medicine' proposed by Arthur Kleinman and many thereafter.

Management of diabetes – knowing how to live with diabetes

As already described, differences also show in relation to treatment initiatives. In some cases this is the result of a difference in understanding what is causing the diabetes, but we have also found that patients that have corresponding views to that of their providers will still enact treatment differently to what they have been advised. In the study a woman in her early sixties, knowledgeable about diabetes, and with an understanding of the causal factor aligned with the medical world skips part of her medication because she feels she doesn't need it. Explaining her oral medication she said: *"Then it went up to 500 twice a day, then it went up to 500 thrice a day, but I take it only twice a day"* Or to give another example a woman, of the same age, skips her medication for a couple of days when she feels fine and her blood glucose measurement is ok.

> Informant: I can, not take my medication for two days, and if tomorrow I test my blood sugar it might be 5.3.
> Interviewer: So you don't have to take you medication everyday?
> Informant: No I don't have to, because its controlled
> Interviewer: What does the doctor say?
> Informant: He tells me to take my medication everyday.

Actions such as these are considered highly illogical by health care professionals as she is actively endangering her long term health, but there was no doubt that she was fully aware of the potential long term complications of diabetes: She explained that her mother had died from diabetes and had a sister who had one of her legs amputated. *"She got it bad"*, as she said. These and similar examples illustrate how the same body can tell different stories to different people. Where providers see an ill body for which medication is intended to slow down the inevitable deterioration, the patient might feel fine and hence see limited need for medication.

'Anchoring' diabetes management into the everyday – the constant choice-making

The everyday management of diabetes is best understood as a series of 'smaller' decisions where diabetes related issues are considered together and against the many other, and sometimes-competing, non-diabetes related factors that people manage in their lives (Hunt and Arar 2001: 362). Looking at how people live with diabetes naturally highlights that their life is full of different factors that take time and require emotional and sometimes also economic investments. Regardless of whether patients do regard the advice and information given by their provider as the right thing to do, competing influencers such as children, partners, other family members, friends, work, sports and economic issues are some of the many other factors that people with diabetes are exposed to and obliged consider. This naturally affects the possibilities of following advice and directions.

In addition it is also important to highlight that most people, to a varying extent and with varying frequency, feel the need to manifest for themselves, and to others, that they are not defined by their diabetes which often results in behavior that is directly opposite to what providers advise as good sense. A man in his late fifties, who had quit alcohol because of providers advice, had no plans to *"give up on"* his breakfast eggs and butter: *"I love my butter and eggs and I probably have about six eggs a week and half a pound of butter too….my nurse does not like that"*.

However, most often we have found that patients will divert from the guidelines and direction given by providers for limited periods of time and show remorse. Feeling 'ashamed' or 'guilty' as informants called it, shows how the managing self, blames itself for any shortcomings. *"I am naughty, I really am. I have been that for more than a month now"*, as one of the informants said when talking about her diet. It also shows how patients come to internalize or appropriate perspectives from providers as part of their perspectives - even some that conflict with their own understandings. Showing that patient and provider practice are rarely that far apart as Ferzacca has pointed out (Ferzacca 2000: 29), but also leading to a situation in which patients are never far from 'failure' one way or the other.

Self-management as compliance

The differences in patients' and providers' perspectives lead to providers labeling patients' perspectives and behaviors as irrational, foolish, lacking understanding of diabetes and presenting an obstacle to achieving good control of the patient's diabetes. Providers use terms like non-compliance or non-adherence when patient perspective or behavior is in opposition to what they have been told by providers. However to providers self-management seems to be defined as complying with the treatment they have outlined. This overriding perspective ignores the vital consideration that patients will not always subscribe to the same logic and rationality as providers, rather naïvely disregards many other factors in the life of a person living with diabetes, and leaves the responsibility for patients' lack of control to the patients themselves. Providers' attempts to assist the patients in achieving control tends to take the form of 'education'; giving rational arguments for the treatment regimen they have prescribed to the patient, and explaining how bad complications can become if they don't comply with the regimen. This they say is in order to 'get patients to realize the seriousness of the disease' and motivate compliance. However, patients are in general well aware of the seriousness of the disease. It could therefore be concluded that providers' efforts are somewhat misplaced (Hunt and Arar 2001: 362).

Providers intend patients to follow both medical and non-medical advice in an almost prescriptive way, which, they believe, will lead to good control. This validates the argument made by Trostle (1988) that providers' education of patients and their call for 'compliance' and 'adherence' at its core represents a form of control over patients, in which patients are 'blamed' and 'scared' into cohesion (Trostle 1988). They fail to take into consideration the 'reflection-in-action' nature of patients' decision making in which non-diabetes related goals are also weighed in on the anticipation of outcomes that guide their decision making or *sensemaking*, which I will prefer to call it, hereby disregarding the individual's ability to make sense of real world situations (Mamykina and Mynatt 2007: 51).

The current deadlock

A troubling ramification of this is that patients and providers find themselves in a situation in which the concept of self-management is misused in an attempt to coerce the patient into following the treatment regimen outlined by providers with the noble goal of improving patients control. However the result is a situation where the reality of patients' perspectives on, and life with, diabetes, is given inadequate consideration by providers when designing the treatment initiatives. This state of affairs has not led to substantial progress in the treatment of diabetes. It has resulted in unsatisfactory results for the individual, the health care providers, the health care reimburses and society at large with consequent detrimental human and economic costs.

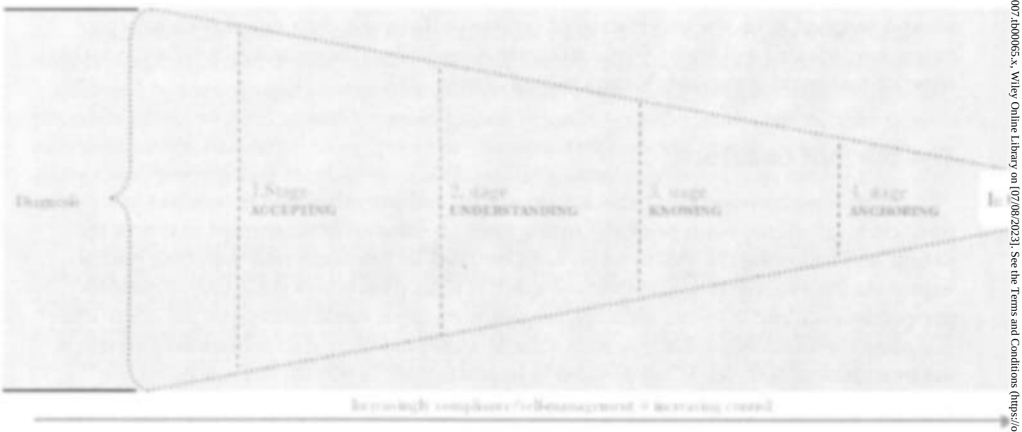
GIVING VOICE TO THE PEOPLE LIVING WITH DIABETES

In order to break with the current "route" I suggest a new route where providers are helped to understand the perspective of each individual patient on diabetes and the factors that impact the way treatment is enacted. A route that acknowledges that the biomedical perspectives on cause, etiology and interventions are already effectively shaping diabetes treatment and that most power is vested in providers.

Striving to provide a simple way to ensure that patient perspectives and views are shared and respected, we have attempted to take into account the many different constraints and factors that providers face when caring for patients with diabetes. Limited time to spend for each consultation, economical constraints, guidelines and regulations from reimbursers and health authorities and economical incentives to focus their efforts on control all place demands on providers. With primary care providers becoming the main provider of diabetes care in many western countries patients will increasingly be met by generalists for whom diabetes is just one of many diseases that they tend to; providers who have a more traditional and 'simple' knowledge and approach to diabetes.[10]

Taking all these factors into consideration we have tried to make a simple model (see below), which providers should find relevant and easy to relate to. Using the model as a point of departure providers will be able to prompt talks with patients about the different key aspects of life with diabetes, and together with the patient decide what to focus on and how to best design treatment initiatives. It is centred around the idea that from diagnosis people with diabetes will embark on what we have called the 'diabetes journey'.

I have already partly described three of the four aspects of the model, and will keep further description to a minimum.



- Accepting: How the individuals accept that their body is no longer producing the insulin needed, and hence intervention, either non-medical, medical or both, is needed. It is important to emphasize the dissimilarity to the 'package deal' thinking, that some providers seem to embrace when they use patients' lack of acceptance of diabetes to explain unsatisfactory control levels. In our studies we have found several examples of patients that have accepted that they have diabetes, but will still not be in full compliance with the prescribed treatment regimen. As I have also attempted to illustrate in this paper there are many other reasons for not following the provider's direction and advice. Thus I would argue for a more relevant use of the concept of acceptance.

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[10] This is the finding we have made through ethnographic studies of diabetes care in primary health care in the UK, DK and US over the last year.

- Understanding: Diabetes etiology and understanding the individual's cause explanations. The principal function is to ensure that providers understand how the patient perceives their diabetes and to make sure that patients and providers discuss these issues together.
- Knowing: The knowledge people have about how to live life with diabetes. Focussing the attention of the provider and patient on discovery of the different treatment initiatives available, and the pros and cons of these. Revealing to providers that the palette of relevant interventions is much wider than the options they perceive.
- Anchoring: The actual employment of treatment initiatives into the everyday life of a person living with diabetes. The many different competing factors in a person's life will be highlighted and included in patient's and provider's shared decision and sensemaking.

It has been portrayed and constructed as a journey because all of our projects have suggested that the four aspects follow each other in the proposed sequence. The journey structure suggests that these four aspects can be regarded as phases towards improved control levels, and that sustained successful control depends on a having addressed all four aspects in sequence. For example, trying to give advice and direction on *anchoring* to a patient without first endeavouring to ensure that you (as a provider) have fully understood their *understanding* of diabetes, and that the patient has fully acknowledged yours, would not be ideal. This finds support in theories on behavioural change such as the Transtheoretical Model, that argue a certain state of acceptance and understanding, and from this readiness for change, needs to be reached for knowledge and information to serve people effectively (Mamykina *et al.* 2006: 935). This understanding is also very well established among providers.

The underlying assumption is that providers and patients need to work together, because a provider trying to force the patient to a specific perspective or treatment intervention will only fail, and undermine their own future advice. Hence providers with the following attitude will be less successful: *"The responsibility of the patient is to understand it as a kind of student/teacher relationship - that the patient is listening to the physician and understands what kind of illness he has, why we are going to treat it, and that they accept the insulin"*, said by a general practitioner.

It is important to understand that the journey does not end with the patient becoming in control. Life constantly changes hereby influencing the ways by which you live with diabetes and for people with diabetes this among other things includes a gradual deterioration of their diabetes. Hence people might get in control for a period of time, followed by a setback with unsatisfactory control levels; following a cyclical process that seems to characterise changes of habits (Smith *et al.* 2006: 284). Therefore providers and patients should continuously engage in fresh discussion in order to ensure that the right interventions are chosen - hereby actively avoiding that provider and patient believe that they have finished discussing the aspects of accepting, understanding and knowing.

FUTURE PERSPECTIVE

The diabetes epidemic is reaching enormous proportions, and the importance of addressing the primary cause of this increase – the extreme rise in the number of overweight and obese people – is apparent. This however, should go hand in hand with an improved approach to diabetes management, hereby improving life quality and quantity through an increasing number of people with good HbA_{1c} levels, which should ultimately bring about enhanced spending practice.

The economic case for improved diabetes management is making itself ever clearer. Studies conducted by a Danish team of economists and medical scientists argue that the economic consequence of improving care from current Danish practice to one following national and international recommendation would be a 40% decrease in the total medical cost for diabetes (Green et al. 2006: 9)[11]. In the US - the team argues that their findings would apply to most western countries – the savings in 2002 would have amounted to approximately 40 billion USD.[12] However the problem of identifying the most successful and cost effective interventions to get there remains.

The presented model can serve as the overall framework for how to identify the right interventions. It is still a work in progress; the model will necessarily evolve to incorporate further adjustments and corrections, which is already taking place in a cooperative effort with our client, but it has been supported by research conducted by the client and by a recent project that focused on the training of doctors and nurses in primary health care to better understand and act on the 'psycho-social' aspects of diabetes. This training resulted in lowered control level among their patients.[13] Hence, despite the need to hone the model, I would not hesitate to assert that the premises on which it is founded are correct: That there is a need for a new direction in diabetes management, a change in which the patients' perspectives on diabetes and their everyday sensemaking is taken into unprecedented consideration. A mode where compliance or non-compliance disappear as the organizing principles substituted for a mode where real acceptance of the patients' perspectives and ideas paves the way for self-management in its true sense, where providers together with patients choose the right treatment interventions to achieve good control.

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[11] The research presented is based on the actual spending in 2001 and the spending that would have been had patients been granted the care following national and international advise from 1985 and onwards (Green et al 2006: 6-11).

[12] The premise of this calculation is that the of cost for care of people with diabetes in the US could be lowered with the 43%, that Green et al. Argue is the case for Denmark. The actual US cost in 202 was $91.8 billion (American Diabetes Association 2003, http://care.diabetesjournals.org/cgi/content/full/26/3/917).

[13] Due to confidentiality issues, I cannot go into detail

The model essentially presents a framework for understanding and for the design of interventions. At macro level it gives decision makers a better understanding of the issues that are the most prevalent and significant, and most importantly how to address them. At micro level it frames the use of current detailed treatment guidelines, questionnaires and interventions available for providers in guiding their decision-making on appropriate interventions or how to design new and more efficient tools, hereby giving them a better understanding of how to best serve the need of the patient on the other side of the table.

If the lives of millions of people living with diabetes are to be truly changed for the better, it is paramount that numerous concrete and practical interventions are designed. I would argue that the presented model may represent a good point of departure, and that anthropological and ethnographical work can make a difference here, by providing a deeper understanding of the experiences of people with diabetes while doing this in a manner with optimal operational relevance for providers. It is not until we have fundamentally changed the health care system that diabetes care can be changed for good to the benefit of people living with diabetes.

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