

An aerial, high-angle photograph of a large crowd of runners participating in a marathon. The runners are densely packed, filling the entire frame. Many are wearing white t-shirts, and some have race bibs visible. The perspective is from directly above, looking down on the runners as they move across a paved road. The overall tone is busy and energetic.

## CHAPTER 2

### **No impact, no worries?**

**A systematic review of emotional, cognitive, and behavioral responses to the diagnosis of type 2 diabetes**

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## **ABSTRACT**

Previous research suggests that patients with type 2 diabetes adjust quickly to their diagnosis, but most studies tend to focus on emotional responses to diagnosis. This systematic review also examines newly diagnosed patients' cognitive and behavioral responses. Findings are based on 23 empirical studies, published in English between 1996 and 2007, and examining psychological outcomes in type 2 diabetes in the first year after diagnosis. The studies' methodology and limitations are taken into account, presenting them in order from the most to the least rigorous design. A further distinction is made between screening and other diagnoses, following the focus of the studies under review. This review confirms that the diagnosis of type 2 diabetes has little long-term emotional impact, if at all, regardless of how patients are diagnosed. Examination of cognitive and behavioral responses reveals that patients underestimate the seriousness of their diabetes, overestimate their ability to control it and show limited engagement in the self management of their disease. Furthermore, results suggest that patients are not so much concerned about the long-term threats to their health but rather focus on the short-term impact of the disease and its treatment on their daily lives. Symptom experience, prior knowledge and the way in which the disease is communicated and treated are put forward as potential explanations for variations in adjustment. However, conclusions must remain tentative, as the number of studies examining cognitive and behavioral responses is limited, and includes many less rigorous, cross-sectional and/or retrospective designs. Nevertheless, these investigations into patients' cognitions and behaviors suggest that the lack of emotional distress does not necessarily indicate a successful adjustment. Mild emotional reactions may instead reflect patients' tendency to avoid dealing with and managing their diabetes, ultimately undermining the effectiveness of early detection and treatment.

## INTRODUCTION

Type 2 diabetes is a serious and chronic disease that begins in middle age and has major and lifelong repercussions. Characterized by chronically elevated blood sugar levels, type 2 diabetes generally begins with minimal symptoms. When left untreated, the disease is associated with severe vascular complications such as cardiovascular disease, blindness, foot amputation and kidney failure. While actual manifestation of these complications may take years, the newly diagnosed patient is often immediately confronted with a barrage of medical treatments and lifestyle changes geared to normalizing blood sugar levels and decreasing cardiovascular risk. The success of the treatment relies heavily on the patient's ability to manage the illness on a daily basis and for the rest of one's life, a difficult task which can have considerable impact on one's family, work and social life (Glasgow & Eakin, 1998).

This systematic review examines how recently diagnosed patients adjust to living with type 2 diabetes during the early stages of their disease. The focus on newly diagnosed patients is particularly relevant given the recent and dramatic increase in the prevalence of diabetes, with more than 200 million patients worldwide (Zimmet, Alberti, & Shaw, 2001; Wild, Roglic, Green, Sicree, & King, 2004). This increase is in part due to ageing populations and increasingly sedentary lifestyles, but more active case finding and screening programs among at risk-populations have also played an important role. Such programs recognize that a large number of patients remain undiagnosed, untreated and unaware of their illness, and logically assume that early detection and treatment will prevent, or at least delay the onset of long-term complications (Engelgau, Venkat Narayan, & Herman, 2000). However, the success of such programs ultimately depends on the patients' ability to accept and manage their disease.

Up till now, most research would suggest that newly diagnosed patients adjust relatively quickly to their diagnosis. From a large number of studies across a wide range of illnesses we know that patients can experience their diagnosis as a time of personal crisis and emotional upheaval, but this period of upheaval is usually relatively short, with most patients adapting to their illness within a few months (Sidell, 1997; Stanton, Collins, & Sworowski, 2001). Furthermore, positive emotions such as relief and affirmation are not unusual (Cassileth, et al., 1984). One could conceive that diagnoses in asymptomatic conditions such as type 2 diabetes could be more distressing, particularly in screening like conditions in which patients do not feel ill and are therefore not expecting the diagnosis (Doust, Mannes, Bastian, & Edwards, 2003). However, an extensive review across a wide range of illnesses found that screening was only associated with a brief period of distress, if at all (Shaw, Abrams, & Marteau, 1999). Similarly, a recent review on screening for type 2 diabetes also found that neither the screening procedure nor the diagnosis had any effect on patients' distress or well-being in the following year (Adriaanse & Snoek, 2006). This finding goes against much of the literature which often describes the adaptation to a chronic illness as a long-term process of bereavement in which patients must go through a set series of emotional stages in accepting and integrating their illness (Lorig, et al., 2000).

However, a lack of emotional distress does not signify in itself that patients have come to terms with their illness. Adjusting to a chronic illness such as type 2 diabetes poses a dilemma which also requires considerable cognitive and behavioral effort (Cameron & Leventhal, 2003). In cognitive terms, patients must accept the reality of the health threat, recognize the need for behavioral change and feel able to set goals and make plans to achieve these changes. Behaviorally, patients must adapt their lifestyles to accommodate diabetes self-care. Studies on diabetes repeatedly find that a significant proportion of patients fail to engage in their self management (Peyrot, et al., 2005), making it questionable whether mild emotional reactions do in fact reflect successful adjustment.

The goal of this systematic review is therefore to critically assess recent empirical evidence regarding the emotional, cognitive and behavioral responses of patients newly diagnosed with type 2 diabetes, also examining potential reasons for variations in patients' adjustment in the first year after diagnosis.

## **METHODS**

This review is based on recent literature, published in English from 1996 to 2007, and listed in the Psych-info, Medline, Cochrane and CINAHL databases. We restricted our search to this period given the recent epidemic growth in the prevalence of diabetes and the increasing research and public awareness on diabetes in the last decade. Search terms included *emotional*, *cognitive* and *behavioral* terms, focusing on patients with type 2 diabetes and their outcomes in the first year after diagnosis (see Table 1). Initial selection of studies was based on the information given in the abstract. Studies which did not focus on newly diagnosed patients but clearly examined their reaction to diagnosis and/or adjustment in the first year were also included for further perusal. We included prospective, cross-sectional, and retrospective studies, designs with and without control groups, and data-collection involving either questionnaires, interviews, or focus groups.

Subsequently, studies identified in our search were reviewed by two of the present authors. Overall, few studies focused on recently diagnosed patients or included an analysis of time since diagnosis. In addition, the majority of studies were excluded due to their exclusive focus on biomedical parameters. Other exclusion criteria were an inadequate description of study populations, designs or results, non-empirical studies (e.g., reports, advice or opinions), and studies in which patients had already received some form of psychological intervention. Based on this last criterion, the majority of studies using focus groups were excluded as these took place within a diabetes educational setting. The initial selection was lenient, and when in doubt, the full-texts were collected or contact was made with the authors. The net result was 23 studies (described in 29 empirical articles and one dissertation) studying the impact of and adjustment to a diagnosis of type 2 diabetes.

**Table 1: Search strategy**

Key terms	Results		
	Medline	Psychinfo	Cinahl
1. Type 2 diabetes (niddm, etc.) not child, adolescent or youth,...)	40674	483	4187
and			
2. Newly diagnosed (new / recent onset, screen*...)	7245	98	1244
and			
3a) Emotion* (anger, fear, anxiety, denial, depression, relief...)	94	21	135
3b) Cognitive (cognit*, attitude*, perception*, personal model*, belief, illness representation*, knowledge, concern*,...)	225	36	443
3c) Coping (adjustment, adaptation, reaction, psychosocial ....)	188	12	222
3d) Adherence (compliance, self-mgt, self-care behavior)	32	13	210
<b>Result prior to selection</b>	469	59	597
<b>Result after selection</b>	19	6	10
<b>Net result</b>		<b>23</b>	

Pubmed = electronic database of the National Library of Medicine (incl Medline)

Psychinfo = electronic database of psychological (-related) journals

CINAHL = the Cumulative Index to Nursing and Allied Health Literature (CINAHL)

### *Evaluation of individual studies*

In evaluating the strength of the studies we followed the system developed by the National Heart, Lung and Blood institute (NHLB), categorizing studies based on their ability to allow for causal inferences (cf. Faith, Fontane, Baskin, & Allison, 2007). This system differentiates between randomized controlled trials with rich (category-1) versus limited body of data (category-2), non-randomized trials and observational (cross-sectional) studies (category-3) and focus groups (category-4). The strength of empirical evidence is assessed based on the number of studies falling in each category. The present selection, described in Table 2 (see pages 30-34), included three category-2 studies, 18 category-3 studies, and two category-4 studies, but no large-scale randomized trials (category-1). Six studies were prospective, but only three of these compared newly diagnosed patients with other groups and could be considered to fall in the second category. The other three thus fell in the third category. Fifteen studies were observational, using questionnaires or interviews to assess patients at a single time point (category-3). Of these, eight focused on patients diagnosed less than one year ago, while six were retrospective, requiring respondents to reflect on experiences many months and up to 30 years in their past. Two studies used focus groups and therefore fell into the fourth category. The sample size in most studies was limited (5 studies had less than 20 participants, 8 had between 20 and 100 participants while ten studies had more than 100).

We have taken these limitations into account, following the NHLB in presenting studies with respect to their ability to allow for casual inferences on patient's emotional, cognitive, and behavioral responses. Studies will be presented from the most to the least rigorous design (prospective, observational or focus group). In addition, we also differentiate between studies involving patients diagnosed less than one year ago and those retrospectively assessing patients' adjustment. We will evaluate the state of evidence for each outcome and underline important strengths and limitations of the studies. Finally, we will examine the selected studies for evidence of factors which influence patients' adjustment, also taking aforementioned criteria into account.

## **RESULTS**

### **Emotional responses**

Fifteen of the 23 studies investigated emotional responses of patients newly diagnosed with type 2 diabetes (see Table 2). The studies with the most rigorous design were those investigating emotional reactions to screening. Given this distinction between screening and other diagnoses we have chosen to take this into account when presenting patients' outcomes.

\* *Screen-detected patients*: Five studies examined emotional outcomes in screen-detected patients. In a series of prospective studies, Adriaanse and associates examined the psychological consequences of screening in terms of emotional adaptation well-being and perceived mental health, from before diagnosis to 12 months later, comparing screen-detected patients (n=116) with non-diabetics, at-risk patients and patients diagnosed via the general practice (Adriaanse, Snoek, & Dekker, et al., 2004; Adriaanse, Dekker & Spijkerman, et al., 2005; Adriaanse, Snoek, & Dekker, et al., 2003; Adriaanse, Snoek, & Dekker, et al., 2002). They found that participants evaluated the screening process very positively, and there was little indication for any lasting anxiety, regardless of the result. In interviews with 20 screen-detected patients, 19 reported some surprise at diagnosis but only one reported negative feelings. The vast majority showed continued healthy emotional outcomes (e.g., well being and perceived mental health) two weeks to one year after diagnosis, with scores comparable to non-diabetic and at-risk populations, and significantly better than those diagnosed in the general practice.

In another prospective study, a screening trial among 1253 veteran-outpatients found that a positive diagnosis had no negative effects on well-being or perceived health 12 months later (Edelman, Olsen, Dudley, Harris, & Oddone, 2002). This study was limited to male outpatients, of which 95% had co-morbidities, which could diminish differences between diabetic and non-diabetic patients. Nevertheless, findings were identical to those of Adriaanse and associates.

Three observational studies also examined screening related outcomes. Skinner and colleagues examined the impact of the screening program itself, and found that participants reported little anxiety at screening (2005). However, this study took place before the screening and did not examine how patients ultimately respond to their diagnosis. Park examined emotional outcomes at time of and six weeks after screening, comparing the emotional outcomes of participants who did and did not take part in screening with those ultimately diagnosed. Anxiety was generally low, but significantly higher among subjects participating in the screening, and particularly high among those ultimately detected. However, this study included only six detected patients with measurements taking place relatively shortly after diagnosis (Park, 2001). Finally, another study among screen-detected patients diagnosed 3 to 33 months previously found that most patients reported low anxiety, depression and diabetes related distress in the first few years, although a significant number did report clinically relevant levels of anxiety (27%) and depression (22%) (Thoolen, De Ridder, Bensing, Gorter & Rutten, 2006). Overall, these studies confirm that screening has no long-term emotional effects for most patients and only limited short-term effects.

\* *Other newly diagnosed:* Ten studies examined emotional outcomes of patients regardless of the manner of diagnosis. Three studies had a prospective design, focusing on changes in the first year after diagnosis. Adriaanse and associates found that patients diagnosed in the general practice reported lower well being and perceived health, and more symptom distress than screen-detected patients at diagnosis (2004). However, to put this into perspective, mental health was relatively high in both groups while those diagnosed in the general practice improved significantly in symptom distress and well being in the subsequent year.

Nichols and Brown (2004) identified new patients from their medical records and compared those who had (n=105) and had not (n=168) received a diagnosis from their GP with healthy controls (n=589), examining health related quality of life over 12 months. Patients had significantly poorer physical health but similar mental health to healthy controls at baseline. There were no significant changes in the subsequent year, regardless of whether or not patients received a diagnosis. There was considerable variation with one-third of patients reporting poor mental health. However, it was not known when patients actually received their diagnosis while a significant number did not complete the second questionnaire.

Emotional adjustment in the first year was also assessed by a series of repeated interviews with 40 patients newly diagnosed with type 2 diabetes (Peel, Parry, Douglas, & Lawton, 2004). This study found that although there was considerable variation in responses, strong emotional reactions to diagnosis were rare. While asymptomatic patients tended to experience more shock and denial most patients overcame these negative emotions within a few weeks.

The other seven studies were observational. These studies suggest that there is considerable variation in patients' emotional response to diagnosis. One study examined the emotional adjustment of 71 patients two weeks after diagnosis, finding that half reported negative emotions, while one-quarter of the 71 also felt unable to cope (Pibernik-Okanovic, Roglic, & Prasek, 1996). Those with the most negative outcomes were found to have the poorest metabolic control at 12 months, suggesting that their emotional distress may be more pervasive. Two other studies among patients diagnosed less than one year, stressed the variation in emotional responses, but failed to indicate the number of patients actually experiencing distress (Richards & Morris, 2001; Everett & Kerr, 1998).

The remaining four studies were retrospective, asking patients to reflect on their diagnosis up to 30 years in the past. Overall, these indicate that patients experience a wide range of emotions at diagnosis, including shock, anxiety, denial, anger, fear, and loss of control on the one hand, and relief and affirmation on the other (Dietrich, 1996, Gillibrand & Flynn, 2001). The two studies that quantified this found that between one-quarter and one-half experience strong negative emotions at diagnosis (Beeney, Bakry, & Dunn, 1996; Lo & Maclean, 2001).

#### *Summarizing emotional responses*

There is considerable variation in patients' reactions at diagnosis. Up to one half may experience negative emotions, but mild and even predominantly positive reactions at diagnosis are not uncommon. Overall, the more robust studies confirm that the diagnosis of type 2 diabetes has little long-term emotional impact, if at all. As expected, screening was also found to have little emotional impact in the short or long term while studies suggest that variations in responses may be more related to patients' symptom experience than the manner of diagnosis.

#### **Cognitive responses**

In total, 13 studies examined the beliefs, perceptions and attitudes of newly diagnosed patients. The predominant themes which were investigated were perceptions of the health threat, self-efficacy and controllability of diabetes, and patients' concerns. These three themes will be discussed below, again distinguishing between screen-detected and other newly diagnosed patients.

#### *Perceptions of the health threat*

Seven observational studies explicitly investigated threat perceptions, four focused on screen-detected patients, three in patients regardless of their diagnosis.

\* *Screen-detected patients:* Adriaanse and associates used questionnaires to investigate perceived risk and seriousness among participants prior to a screening trial (Adriaanse, et al., 2003) and interviews to assess patients' perceptions two months later (Adriaanse et al., 2002).

Some 60% of participants considered diabetes to be (very) serious, but they generally underestimated their personal risk. People more at risk gave better risk estimates, but they also considered diabetes to be less serious; screen-detected patients, in particular, were less likely to perceive diabetes to be serious. When screen-detected individuals were subsequently interviewed, only 1 in 20 patients considered his or her own diabetes to be serious, 70% described their condition as mild.

Other studies on screen-detected patients show similar results. Skinner and associates (2005) examined threat perceptions of screening participants and found that 59% agreed diabetes was serious, but only 37% expected diabetes to have a negative impact on their life, if diagnosed. Participants who considered diabetes to be more serious and have more consequences were also more anxious at screening. However, perceptions of newly diagnosed patients were not compared to diabetes free individuals. Park also found that six weeks after screening, participants who perceived diabetes to be more serious experienced significantly more anxiety (2001). However, patients who were ultimately diagnosed rated the consequences of diabetes lower but differences were not significant, most likely due to the small number of patients detected ( $n=6$ ). Finally, Thoolen and associates examined perceived seriousness and personal vulnerability (consequences) in screened patients detected 3 to 33 months previously and found that 48% perceived diabetes to be serious but only 28% considered their own diabetes to be serious (2006). These threat perceptions increased with time since diagnosis and number of complaints, while perceived vulnerability was positively associated with all measures of emotional distress ( $r=.45$ ,  $P<.01$ ).

\* *Other newly diagnosed:* From the three descriptive observational studies on newly diagnosed patients, we can conclude that the majority consider diabetes to be a serious health threat. But, as with screen-detected patients, they do not always reflect this on their own condition and also tend to avoid thinking about future potential threats (Dietrich, 1996; Gillibrand & Flynn, 2001, Lawton, Peel, Parry et al., 2005). Asymptomatic patients have a particularly difficult time accepting their diagnosis, needing more confirmation than other patients (Peel et al., 2004) and, as with screen-detected patients, generally do not give their diabetes any personal meaning (Adriaanse et al., 2002).

### *Self-efficacy and Controllability*

Perceptions of treatment effectiveness, control and self-efficacy give an indication of how well patients feel able to deal with the potential health threat of diabetes. Seven observational studies discussed such perceptions. Two studies focused on screen-detected patients, five on newly diagnosed patients in general.

\* *Screen-detected patients*: Interviews with 20 patients, detected two months previously, found that the majority recognized the necessity for lifestyle change. More than half felt confident that they could do something about their diabetes themselves by adjusting their diet and taking medication (Adriaanse et al., 2002). A study assessing self-efficacy among 196 screen-detected patients found that three-quarters reported a high confidence that they could manage their disease but significantly less were actually engaged in self care (Thoolen et al., 2006).

\* *Other newly diagnosed*: The five studies on other newly diagnosed patients also find that more than half are confident about their self-management ability (Pibernik-Okanovic et al., 1996; Richards & Morris, 2001; Dietrich, 1996; Everett & Kerr, 1998; Gillibrand & Flynn, 2001). For example, Pibernik and associates found that 74% of patients felt able to cope with the disease two weeks after diagnosis while Richards and colleagues found that “nearly all” patients were (very) confident in their self-care three months after diagnosis, particularly with regard to exercise and dietary goals. Finally, three studies using interviews found that being diagnosed with diabetes can also diminish patients’ feeling of control over their life, as they become increasingly dependent on health care providers and specific medical regimens (Dietrich, 1996; Everett & Kerr, 1998, Gillibrand & Flynn, 2001). In the one study examining this relationship (in screen-detected patients), lower self-efficacy was associated with higher emotional distress (Thoolen et al., 2006).

### *Concerns*

Eight observational studies investigated the concerns which patients have about their disease, and in a sense this could be another way of looking at how patients perceive the threat and controllability of their diabetes. One study inquired about concerns in screen-detected patients, seven in other patients.

\* *Screen-detected patients*: The one study among screen-detected patients found that most patients had no major concerns, although 60% were somewhat worried about the implications of dieting, as this often entailed major adjustments in their lifestyles (Adriaanse et al., 2002).

\* *Other newly diagnosed*: Studies among other newly diagnosed patients indicate that treatment is a major concern. Two studies assessed the concerns of patients by questionnaires (Woodcock & Kinmonth, 2001; Beeney et al, 1996). Woodcock and Kinmonth assessed the concerns of 250 type 2 patients one year after diagnosis. In an open question, “*following dietary advice*” was cited most often, followed by fears of declining health. Beeney and associates retrospectively assessed concerns at diagnosis in 1159 diabetes patients (of which 785 type 2) diagnosed an average 10 years. Type 2 patients most often reported diet to be their major concern at diagnosis (21%), followed by injections (15%), complications (13%)

and lifestyle impact (13%). Both studies thus indicate that self-management concerns appear as often as health-related concerns while some 50% of patients describe 'diabetes-related management' as their major concern.

Concerns of patients also came to the fore in descriptive studies using interviews and focus groups. These results suggest that patients are not so much concerned about the long-term threats to their health but rather focus on the short-term impact of medical treatment and lifestyle changes on their daily lives, diet in particular (Gillibrand & Flynn, 2001, Everett & Kerr, 1998). Furthermore, for many patients having diabetes was synonymous with having to take injections, a topic which many patients were concerned about regardless of whether it was part of their treatment (Beeney et al., 1996; Everett & Kerr, 1998). Patients wanted to appear and act as normal as possible and continue their lives as usual, minimizing the intrusiveness of the diabetes (Gillibrand et al., 2001; Hörnsten, Sandström, & Lundman, 2004). Taken together these studies suggest that, for newly diagnosed patients, the day-to-day self-care can be more intrusive than the long-term complications.

#### *Summarizing cognitive responses*

More than half of the studies examined cognitions in newly diagnosed patients, but all were observational. Many studies described outcomes without indicating their relative occurrence while associations between cognitive and emotional outcomes relied on cross-sectional evidence. Regardless, the findings indicate that patients with type 2 diabetes downplay the seriousness of their disease and overrate their ability to control it. This appears to have adaptive value, as those patients who perceived their disease as less serious also reported less emotional distress (three studies) while higher self-efficacy was also associated with lower emotional distress (one study). Finally, newly diagnosed patients are particularly focused on the short-term impact which diabetes has on their daily lives, in which diabetes treatment is often considered more intrusive and problematic than long-term complications.

#### **Behavioral responses**

Seven studies investigated behavioral responses in newly diagnosed patients. The three prospective and four observational studies all examined (specific) self-management behaviors. Four focused on screen-detected patients, three on newly diagnosed patients in general.

\* *Screen-detected:* A study among 196 screen-detected patients found that most patients report low self management in the first year after diagnosis with scores comparable to patients diagnosed two to three years previously (Thoolen et al., 2006). Medication adherence was higher than dietary and exercise behaviors. Findings were based on participants planning to take part in a self-management intervention; nonparticipants reported slightly, but significantly, more self-management behaviors (Thoolen et al., 2007).

The three other studies on screen-detected patients focused on physical activity and included two observational studies and one prospective study. Baan and associates compared 118 screen-detected patients with 153 subjects with insufficient (IGT) and 745 with normal glucose tolerance (Baan, Stolk, Grobbee, et al., 1999). They found that time spent on physical activity decreased significantly with increasing IGT, while screen-detected diabetes patients showed the lowest activity scores. However, given that activity levels were only assessed at time of screening, it does not indicate how patients subsequently respond in terms of self care. A similar study assessed physical activity comparing new screen-detected patients (n=71) with non-diabetics (1100), but also included 97 patients diagnosed in the general practice in the last four years (Fulton-Kehoe, Hamman, Baxter, & Marshall, 2001). Patients with diabetes reported significantly lower levels of physical activity than those without diabetes, although this relationship diminished when controlling for BMI. There were no significant differences between new-detected patients and those with a longer diagnosis. Finally, Edelman and colleagues prospectively examined changes in exercise behaviors over one year, comparing screen-detected and diabetes-free patients (2002). Exercise levels did not differ at baseline and there were no significant changes 12 months later. However, the population was limited to male out-patients, the majority of whom were suffering from (multiple) comorbidities. Taken together, these findings suggest that screen-detected patients report relatively low levels of self management at diagnosis and do not improve over time.

\* *Other newly diagnosed:* The remaining studies examined dietary behaviors (two studies) and glucose monitoring (one study) in newly diagnosed patients. Miller and Brown (2005) examined 20 couples' adjustment to dietary management of type 2 diabetes in the first two years after diagnosis using repeated interviews. Three couple categories emerged, representing their flexibility, roles, rules and communication in adapting to their diet. Initially, five couples were cohesive (teamwork approach), seven were enmeshed (nondiabetic spouse responsible for the diet) and eight were disengaged (patient solely responsible). A year later, the majority of couples were disengaged (n=14), one couple remained cohesive, and four couples remained enmeshed. Although dieting behavior was not explicitly measured, few patients considered themselves successful dieters, citing personal problems, barriers, and interpersonal conflicts as reasons for failure. Success was primarily perceived to be a question of willpower. Another study also examined diet in 16 newly diagnosed patients, interviewed in the first session of a counseling program (Kasila, Poskiparta, & Kettunen, 2003). One month after diagnosis, all patients recognized the need for diet, but less than half (7/16) were actively dieting; the majority (nine) were still in the contemplative or preparatory stage of change and had not taken action, five were actively engaged in improving various aspects of dietary self care, and only two patients had no need for change.

Lawton and colleagues examined glucose monitoring in 40 newly diagnosed patients using three interviews at 0, 6 and 12 months (2004). The number of patients monitoring their blood-sugar levels increased from half to two-thirds at one year. Monitoring had the potential to both stimulate and undermine self-care behaviours: it heightened patients' awareness of their asymptomatic condition and the impact of lifestyle but could also amplify a sense of failure when readings remained consistently high. Patients who were more positive were more successful in controlling their diabetes.

#### *Summarizing behavioral responses*

Overall, these findings suggest that both screen-detected and other newly diagnosed patients are not sufficiently engaged in their self-management activities, lifestyle behaviors such as diet and physical exercise in particular. However, firm conclusions are difficult, given the limited number of studies, lack of control groups, an observational and retrospective design, and narrative description of results. Furthermore, all studies based their findings on self reports.

#### **Adapting to type 2 diabetes: Integrating emotional, cognitive and behavioral responses**

In this section, we have tried to disentangle and describe patients' emotional, cognitive and behavioral responses following a diagnosis of type 2 diabetes. However, from a self-regulatory perspective, it must be recognized that the interaction between these responses determines how patients adjust to their illness. Some evidence for this was found in the relationship between patients' perceptions of the seriousness and controllability of their disease, the impact which it has on their lives, and the emotional distress which they experience. However, most studies focused on one specific aspect, either emotions, cognitions or behaviors.

Four studies took a more general integrative approach. Pibernik and colleagues (1996) found that patients who adopted more positive attitudes towards their diagnosis at two weeks, generally felt better able to cope and showed better metabolic control and weight loss at 12 months. Similarly, in a retrospective observational study, Lo and Maclean (2001) found that levels of positive emotions were related to successful adherence while negative emotions undermined health behaviors. Premorbid beliefs, specifically, perceptions of risk and lifestyle also determined long-term coping and self-management behavior. In a third study, interviews with patients at the extremes of good and poor metabolic control found that the most committed patients were those who had spent little time grieving, quickly taking responsibility for their illness (Savoca, Miller, & Quandt, 2004). At the other extreme were patients who were overwhelmed, had considerable psychosocial problems, little understanding of their illness, but also little energy or priority to deal with it. In interviews with 44 newly diagnosed patients, another study repeatedly found that receiving a diagnosis is

not synonymous with accepting it (Hörnsten et al., 2004). Patients must first reconcile their emotions and adjust their personal meaning before they can begin to deal with their illness. Even then, daily hassles and life problems can interfere with self management, overriding long-term health goals and undermining new routines. All four studies illustrate the importance of emotional, cognitive and behavioral aspects in adjustment. The first two studies base their conclusions on statistical analyses of questionnaires; the latter two on content analyses of in-depth interviews.

All in all, it appears that patients who show less emotional and psychosocial distress at diagnosis and a better understanding of their disease in terms of risk and controllability, also show better self-care and control of their disease in the long run. The evidence would suggest that many patients diagnosed less than one year may generally not experience severe emotional distress or bereavement, but they are also far from integrating the illness and the necessary self-care behaviors into their lives.

### **Variations in psychological responses**

The articles included in this review also indicate considerable variations in patients' responses to diagnosis. In part, these may be related to specific characteristics of the patient, including their psychological status at diagnosis (e.g., Skinner et al., 2005) and social resources such as social support, education, income and ethnic background (e.g., Pibernik-Okanovic et al., 1999; Hornsten et al., 2004; Savoca et al., 2004). In this section, we focus on those factors which repeatedly received attention in the studies, notably, the role of *symptoms, prior knowledge and information provision, and medical treatment*.

#### *The role of symptoms*

Ten of the studies indicate that symptom experience influences patients' reactions at and beyond the diagnosis, none refuted it. Contrary to expectations, many patients have been found to have diabetes-related symptoms at diagnosis, screen-detected patients included; however few experience them as such (Adriaanse et al, 2002; Koopman, Manous, & Jeffcoat, 2004; Parry et al., 2004). For example, Parry and associates found that 52% of patients were diagnosed after visiting the general practitioner for diabetes related symptoms, yet only half of these recognized them as such.

In terms of emotional responses, three interview-based studies found that patients who experienced and recognized their diabetes-related symptoms reported being less surprised and relieved that symptoms were not a reflection of other worse illnesses (Adriaanse et al., 2002; Peel et al., 2004; Savoca et al., 2004). Nevertheless, in three studies using validated measures, higher symptom distress was significantly associated with more emotional distress in the first year after diagnosis, most likely a direct reflection of poorer health (Adriaanse et al., 2005; Thoolen et al., 2006, Edelman et al., 2002).

In terms of cognitions, Thoolen and associates found that number of complaints had a small positive association with perceived vulnerability and a weak negative association with self-efficacy (2006). Another study found a relationship between at risk status and perceived vulnerability in a screening trial but this does not necessarily mean that participants experienced symptoms (Adriaanse et al., 2003). Four narrative studies suggest underlying cognitive processes (Dietrich, 1997; Hornsten et al., 1999, Adriaanse et al., 2002, Gillibrand & Flynn, 2001). These studies describe patients' tendency to downplay their own condition by comparing themselves to more symptomatic patients. The studies also report that many patients only begin to experience distress when the first symptoms appear: not feeling sick means not being sick.

While many studies suggest it, direct evidence for the relationship between symptom levels and perceptions of threat and controllability is weak, while no study examined the influence of symptoms on behavior. Nevertheless, the available evidence suggests that the experience and recognition of diabetes related symptoms do influence patients' adaptation.

#### *The role of prior knowledge and subsequent information provision*

Nine observational studies indicate that newly diagnosed patients have only superficial knowledge of the causes, consequences and treatment of diabetes (Skinner et al., 2005; Peel et al., 2004; Gillibrand & Flynn, 2001; Dietrich, 1996; Koopman et al., 1999;). For example, 59% of patients were unable to give an explanation for their diagnosis (Richards & Murphy, 2001) and 70% of screen-detected patients did not grasp the personal relevance of medical information (Adriaanse et al., 2002). Three studies report that a lack of knowledge can exacerbate the uncertainty which many patients experience while it can also cause (asymptomatic) patients to avoid considering long-term health threats and the need for self-care (Beeney et al., 1996; Gillibrand & Flynn, 2001, Adriaanse et al., 2002).

Six studies describe how relatives and friends with diabetes can be an important source of information, increasing patient's understanding of their illness (Adriaanse et al. 2003; Skinner et al., 2005; Dietrich, 1997; Gillibrand & Flynn, 2001; Horsten et al., 2002; Peel et al., 2004). According to Peel and associates (2004), this previous experience with diabetes makes patients more "prepared", diminishing negative emotions and increasing acceptance. However, the only two studies to quantify this relationship did (Adriaanse et al., 2003) or did not (Skinner et al, 2005) find a significant association between a family history of diabetes and threat perceptions. Furthermore, Adriaanse and associates (2002) found that experience with other diabetics can also lead patients to downplay their own relatively mild condition. As such, a family history of diabetes does not necessarily translate into an increased sense of vulnerability.

Seven studies stress the crucial role which health providers can play in increasing patients' understanding of their illness (Beeney et al., 1996; Dietrich, 1996; Hörnsten et al., 2004;

Parry et al., 2004; Peel et al., 2004; Richards & Murphy, 2001; Woodcock & Kinmonth, 2001). For example, Dietrich found that downplaying and impersonal reactions undermined patients' perceptions and motivation while caring, supportive doctors comforted patients and increased feelings of control. Furthermore, several studies showed that, in contrast to what one might expect of a "bad news" receipt, patients nearly all would have preferred more detailed information at diagnosis, and particularly support in dealing with self-management tasks (Beeney et al., 1996; Dietrich, 1996; Gillibrand & Flynn, 2001; Peel et al., 2004; Richards & Murphy, 2001). Professionals were often formal, lacked time and did not address patients' concerns. While professionals tend to focus on metabolic control and long-term treatment goals, patients focus on day-to-day issues such as how they look and feel, being in control of their lives and being able to fit the treatment plan into their daily routine (Beeney et al., 1996; Woodcock & Kinmonth, 2001).

### *The role of treatment*

Seven observational and two focus-group studies examined how treatment may affect adjustment. Treatment of newly diagnosed patients often begins with lifestyle change alone, particularly when they have relatively few cardiovascular risk factors. Five studies suggest that this, in itself, may cause patients to label their disease as less severe and experience less distress (Adriaanse et al., 2002; Dietrich, 1996; Everett & Kerr, 1998, Gillibrand & Flynn, 2001, Wenzel, 2006). Vice-versa, intensifying treatment can be perceived to confirm the seriousness of an illness while it can also makes patients feel less in control (Gillibrand & Kerr, 2001; Everett & Kerr, 1998). However, only two studies explicitly examined this relationship. Adriaanse and associates (2004) found that more intensive treatment was not significantly related to emotional outcomes; however, newly diagnosed patients who received oral hypoglycaemic agents improved significantly in the first year in terms of both their mental and physical health. Thoolen and colleagues (2006) found that recently detected patients receiving intensive pharmacological treatment reported significantly more distress and less self-efficacy than patients receiving milder care. Distress was particularly high on treatment-related items. However, two to three years after diagnosis, intensively treated patients reported significantly less distress and higher self-efficacy. Furthermore, this study also did not find that more intensive treatment increased perceptions of threat.

Finally, the medical setting in which treatment takes place has also been suggested to play a role in patients' perceptions of and adaptation to diabetes (Lawton et al, 2005). For example, patients generally considered hospitals, and treatment by a specialist versus the general practitioner, to be a confirmation of the seriousness of their condition. Longer waiting times may, in turn, convey less concern.

*Summary: Individual variations in adjustment*

Overall, the notion that symptoms, knowledge, information provision and treatment will influence patients' emotional, cognitive and behavioral responses seems logical but cannot be confirmed among patients newly diagnosed with type 2 diabetes. There is some evidence that a lack of symptoms and a low level of knowledge and experience with diabetes can work hand in hand to undermine perceptions of diabetes as a serious health threat, but more studies are needed. The role which physicians play in informing and treating the patient is clearly described, but needs further testing. The effects of different treatments and settings on patients' responses is less evident, but evidence suggests that more intensive treatments may improve patients' adjustment in the long run.

**DISCUSSION**

This review investigated the emotional, cognitive and behavioral regulation of patients newly diagnosed with type 2 diabetes. Previous studies have shown that screening for asymptomatic conditions such as type 2 diabetes has little emotional impact (Shaw et al., 1999; Adriaanse et al., 2006). This review extended this work to include patients diagnosed via other routes and confirmed that the diagnosis has only short-term emotional impact, if at all, regardless of the manner of diagnosis. Only half the patients experience some negative emotions but these are rarely enduring, while positive reactions to a diagnosis are also not uncommon. In this sense, the myth of emotional turmoil and bereavement after diagnosis is disproved. Diabetes is no different from other illnesses in that patients who are chronically ill generally appear to adjust quickly to their diagnosis (Cassileth et al., 1984).

We also stressed the importance of looking beyond emotional outcomes to patients' cognitive and behavioral responses. From the studies, we can conclude that newly diagnosed patients tend to downplay the seriousness of their disease, overestimate their ability to control it, and appear at the least, just as concerned about avoiding the daily hassles of the disease and its treatment as they are about dealing with the long-term implications to their health. Ultimately, relatively few patients are successfully achieving lifestyle changes in the first year after diagnosis.

These outcomes suggest that newly diagnosed patients do have difficulty in accepting their diagnosis. While distress remains minimal, patients also avoid addressing the realities of their illness. Wiebe and Korbel (2003) have described this type of response as "reality based defensive denial", a set of subconscious defensive processes which help to construct understandings of threatening information while simultaneously alleviating emotional distress. These rational processes include minimizing the health threat, using self-serving social comparisons, and biased processing of health information. The fact that patients are not truly accepting the realities of their diagnosis and are not actively engaging in their self care, could also help to explain why they are not experiencing much emotional turmoil. Indeed,

most convincing were the studies on screen-detected patients which found that lower threat perceptions were associated with less distress.

Such processes of defensive denial have been established over a wide range of diseases, including other asymptomatic conditions such as hypertension and hypercholesterolemia (Cameron & Leventhal, 2003). Indeed, in one of the pioneering self-regulation studies, it was shown that new hypertensive patients tended to consider their condition acute and curable, only slowly recognizing the chronic nature of their illness (Baumann, Cameron, Zimmerman, & Leventhal, 1989). Studies among patients with type 2 diabetes suggest that such defensive denial is effective in minimizing emotional turmoil. Healthier emotional outcomes are associated with the best metabolic control in the long run (e.g., Pibernik-Okanovic et al., 1996). However, there is some concern that inexperienced and asymptomatic patients will continue to avoid dealing with their illness until the first signs of exacerbations (e.g., symptoms and treatment intensification) appear, thereby undermining the effectiveness of earlier detection and treatment.

The presence or absence of symptoms does appear to be an important factor, influencing patients' adjustment to type 2 diabetes, but equally important is whether or not patients experience their symptoms as such. The studies, though primarily observational, suggest that asymptomatic patients do indeed minimize the seriousness of the disease and compare themselves favorably to patients who are worse off. If not feeling ill means not being ill, a large proportion of "asymptomatic" patients could very well continue their unhealthy lifestyles until complications appear, where after it is too late.

We also identified other factors which may potentially influence patients' adjustment. Studies agree that many newly diagnosed patients do not yet understand the full impact of their illness, regardless of family history. They are interested in getting more information, and particularly on how to incorporate treatments into their daily lives as painlessly as is possible. Health professionals can play an important role herein. However, they do not always recognize patients' concerns and often focus more on long-term health threats and not enough on treatments (e.g., Woodcock & Kinmonth, 2001). There is some evidence that treatment may influence psychological outcomes in long-term patients (Dunning, 1998) and this was also suggested by studies in this review. However, this was not confirmed by two more objective studies, which found that while intensive treatments may initially be more distressing, patients are generally better off in the long run, both physically and mentally, due to health improvements (Adriaanse et al, 2004, Thoolen et al. 2006). It is questionable, however, whether asymptomatic patients will be equally appreciative of and adherent to such intensive treatments.

A limitation of this systematic review is that it had to rely on a limited number of studies, of which the majority were observational, narrative and often retrospective. Based on the quality of the studies, we feel that we can draw strong conclusions about the emotional

outcomes, but must be more careful with regard to interpreting the cognitive and behavioral outcomes. The findings in this review therefore need more direct experimentation before firm conclusions can be drawn. That said, the last few years saw a growing number of excellent empirical studies, focusing on screen-detected patients in particular. This reflects perhaps a general recognition that we need to understand the psychological impact of screening and early diagnosis and treatment before such programs become widespread.

In sum, this review finds that a lack of emotional distress does not necessarily indicate successful adjustment in the first year after diagnosis. A substantial number of patients feel unconcerned about the long-term threat to their health and are primarily concerned with minimizing the intrusiveness of the disease on their daily lives. Not engaging in self care behaviors is part of this process and is quite understandable in patients who are, as of yet, asymptomatic. However, from a medical point of view, the importance of early medical treatment and lifestyle change is widely acknowledged, regardless of the symptom experience. This review stresses the importance of making patients aware of the long-term implications of diabetes while simultaneously supporting them in their day-to-day self-care tasks, minimizing the intrusiveness of the disease in both the short and long term. An increasing number of interventions have begun focusing on newly diagnosed patients and these interventions appear to be somewhat effective in increasing patients' knowledge, self care and metabolic control (Olivarius, et al., 2001; Skinner, Carey & Cradock, 2006; Tudor-Locke, et al., 2002). This suggests that newly diagnosed patients may be a particularly effective group on which to focus. However, much more research needs to be done. Finally, this review stresses the importance of looking beyond patients' emotional reactions to diagnosis to consider their perceptions of their disease, and ultimately, how actively they adapt and engage in self-care activities. Patients may experience a wide range of emotional responses, but from a medical viewpoint, whether or not such responses are adaptive ultimately depends on whether or not patients become actively involved in their treatment.

Table 2: Overview of studies examining psychological adjustment in newly diagnosed type 2 diabetes					
PROSPECTIVE, CATEGORY-2					
Author / country	Year	Type - # participants	Study design	Key result	
Hoorn Screening Study Adriaanse et al <i>the Netherlands</i> (5 publications 2002-6)	2004	116 screen-detected 143 non-diabetics diagnosis = 0 wks	Prospective study comparing diagnosed and non-diabetics in a screening. Questionnaires on well being and mental health 2wks prior and 2 wks, 6 and 12 mths after diagnosis.	<i>Emotion:</i> The diagnosis had no substantial adverse or positive effect on well being and perceived mental health up to 1 yr after diagnosis. No sign difference by treatment	
	2004	116 screen-detected 49 diagnosed in GP diagnosis = 0 wks	As above, but screen- detected pts compared to those diagnosed in GP. Questionnaires include symptom distress, mental health and well being. 2 wks before to 12 mths after.	<i>Emotion:</i> Compared to screen-detected pts, pts diagnosed in GP initially reported more symptom distress and lower well-being and mental health but their outcomes improved significantly at 12 mth. Improvement related to treatment.	
	2005	246 high risk, of which 116 screened, 130 non-diabetics diagnosis = 0 wks	As above, but now comparing screen-detected pts with high-risk non-diabetics.	<i>Emotion:</i> Symptom distress and negative well being low in both groups. No change in 12 mths. Symptom distress higher in screen-detected. Negative well being associated with symptom distress	
	2003	217 screen-detected 4435 low-risk diagnosis = 0 wks	Observational study, using questionnaires to assess perceived seriousness of and personal risk for diabetes prior to diagnosis in screen-detected pts and those with low risk. <i>Limit:</i> pts were unaware of diagnosis at time of assessment. Hence not response to diagnosis	<i>Cognition:</i> Perceived risk was very low. Screen-detected pts were more likely to answer either 'I do not know', or rate risk higher. 60% considered diabetes to be a (very) serious condition. Patients and those at high (perceived) risk perceived diabetes to be less serious. Family history increased threat perceptions.	
	2002	40 at high risk, of which 20 screen-detected 20 non-diabetic diagnosis = 2 months	Observational study, using semi-structured interview to assess pts experience of screening and their attitudes towards diabetes.	<i>Emotion:</i> 19/20 patients were surprised but only one was alarmed by diagnosis. <i>Cognition:</i> Screening procedure was positively evaluated and not distressing. New pts had limited understanding of their illness. Type 2 diabetes was not considered severe. Pts had few concerns. Diet reported most often (12/20). Half were confident they could control disease.	
Edelman et al. <i>USA</i>	2002	1253 veterans screened, of which 56 pts detected diagnosis = 0 wks	Prospective study comparing diagnosed and non diabetics in a screening. Questionnaires assessed health related quality of life, before and 1 yr after screening. <i>Limit:</i> selective sample male veterans with significant comorbidities.	<i>Emotion:</i> Screen-detected and non-diagnosed subjects had similar scores on perceived mental health at diagnosis and one yr. <i>Behavior:</i> No difference in exercise between screen-detected and non diabetics at baseline and 1 yr	
Nichols et al <i>USA</i>	2004	498 type 2 589 controls diagnosis = 0 wks	Prospective study comparing diagnosed non diabetics, using questionnaires to assess health, quality of life, at baseline and one yr. <i>Limit:</i> Unclear when pts received diagnosis.	Those with diabetes already reported poorer physical status prior to diagnosis, reflecting their diabetes related symptoms. Mental health status was comparable in both groups. No changes in physical or mental health in the following year.	

PROSPECTIVE, CATEGORY-3				
Pibernik-Okanovic et al <i>Croatia</i>	1996	71 diabetics diagnosis = 2 wks	A prospective study using questionnaires to assess pts metabolic control, weight, emotional adjustment, and coping responses to diagnosis at 2 weeks. Examined association metabolic control /weight at 1 yr.	<i>Emotion:</i> 2 wks after diagnosis, 50% expressed undisturbed adaptation and sense of being able to cope. This group showed best metabolic control and most weight loss 1 yr later. In contrast, the group of 26% of patients with most negative attitudes showed least metabolic control.
Parry, Peel, Douglas & Lawton (4 publications 2004-2005) <i>the UK.</i>		40 newly diagnosed pts with diabetes diagnosis = 0 wks	Series of repeated interviews with pts at or near diagnosis, 6 and 12 months, assessing their manner of and reactions to diagnosis, their perceptions of diabetes (self-care) and the health-care services. <i>Limit:</i> Relative occurrence of emotional and cognitive and outcomes unclear	Variety of reactions depending on route to diagnosis, prior experience with diabetes, symptoms and treatment. <i>Emotion</i> Shock and negative emotions not prevalent in group who suspected diabetes or approached GP with other health problems. When diagnosis was unexpected, reactions varied but disbelief common. <i>Cognitions:</i> All pts would have liked more information and support at diagnosis, particularly about self care. <i>Behavior:</i> Number of pts monitoring blood sugar increased significantly in first yr. Highlights experiences. Examines dieting behavior, and interpretation of failures.
Miller et al. <i>USA</i>	2005	20 couples with newly diagnosed spouse diagnosis < 1 yr	Two repeated interviews (1 yr apart) with couples examining adjustment to dietary management of type 2 diabetes. <i>Limit:</i> follow-up beyond first yr for most pt No measure of self care.	<i>Behavior:</i> Three categories emerged, representing couple's flexibility, roles, rules and communication in adapting to diabetic diet. Shift from cohesive (teamwork approach) or enmeshed (pt dependent on spouse) to disengaged (pt solely responsible). Shift to disengaged also reflected failed diet.
OBSERVATIONAL, WITHIN FIRST YEAR OF DIAGNOSIS, CATEGORY-3				
Thoolen et al <i>the Netherlands</i>	2006	196 screen-detected diagnosis = 3-33 mths	Observational study. Questionnaires assessed pts' emotional (anxiety, depression, distress), cognitive (threat perceptions, self-efficacy) and behavioral (self-management) outcomes, compared time (diagnosis) and treatment. <i>Limit:</i> selective group planning to take part in self-management intervention.	<i>Emotion:</i> Low distress. Distress levels related to treatment Positively associated with vulnerability and complaints. Negatively associated with self-efficacy <i>Cognition:</i> Threat perceptions low but increase with time. 48% consider diabetes serious, <30% consider own diabetes serious. High self-efficacy but lower among intensively treated pts in first yr. <i>Behavior</i> low self care. Medication adherence high, diet and exercise low.
Skinner et al <i>the UK</i>	2005	1189 screened individuals at high risk for diabetes diagnosis = not yet	Observational study using questionnaires to assess participants anxiety and perceptions of diabetes at screening. <i>Limit:</i> not yet diagnosed, not a response to diagnosis	<i>Emotion:</i> Little anxiety at screening. Family history had no effect on anxiety. <i>Cognitions:</i> 60% had some knowledge of diabetes. 20-25% faulty knowledge. Only 37% agreed diabetes would have a negative impact. 59% agreed diabetes was serious, but only 12% agreed with all consequence items. Positive association between perceived seriousness and anxiety.

Author / country	Year	Type - # participants	Study design	Key result
Park <i>the UK</i>	2000	N=355, 239 uninvited 116 invited 6 type 2 pts detected diagnosis=<0 to 6 wks	Observational study (dissertation) on impact of screening and diagnosis. Questionnaires assessed anxiety and illness perceptions 6 wks after screening. <i>Limits:</i> 6 pts detected.	<i>Emotions:</i> Subjects invited to screening were more anxious than those not invited. 6 pts were more anxious 6 wks after diagnosis than diabetes free pts. <i>Cognitions:</i> Positive association between anxiety and emotions, perceptions about diabetes consequences.
Richards <i>the UK</i>	2001	N=56 pts diagnose < 3 mths	Observational study using questionnaire to assess the impact of diagnosis <i>Limit:</i> limited and descriptive analysis	<i>Emotion:</i> Considerable variation in emotions. <i>Cognition:</i> Subjects reported high self-efficacy for taking medication and following diet but were less confident in ability to control disease. Knowledge of diabetes was poor and pts wanted more information; 60% were unable to explain diagnosis.
Baan et al. <i>the Netherlands</i>	1999	1016 screened - 118 diagnosed type 2 - 153 with IGT, and -- 745 with normal GT diagnosis = 0 wks	Observational study. Questionnaires assessed physical activity, comparing diagnosed, at risk (IGT) and healthy subjects at time of screening. <i>Limit:</i> Activity measured at diagnosis, does not indicate change after diagnosis.	<i>Behavior:</i> Time spent on physical activity decreased with increasing glucose tolerance. Screen-detected pts showed lowest activity scores, particularly with regard to bicycling and sports.
Fulton-Keheo et al. <i>USA</i>	2001	1100 non diabetics 71 screen-detected pts 97 pts diagnosed 0-4 yrs diagnosis = 0 wks	Observational study. Questionnaires assessed physical activity, comparing screen-detected pts with other pts and non diabetics. <i>Limit:</i> same as above, but includes other pts.	<i>Behavior:</i> Diabetes pts report significantly lower physical activity than non-diabetics, new detected pts in particular Relationship diminished when controlling for BMI. Differences between pt groups not significant.
Woodcock et al <i>UK</i>	2001	250 patients diagnosis = 1 year	Observational study using open-ended questionnaire to assess pts and nurses concern regarding diabetes	<i>Cognition:</i> Pts focus more on the short-and long term burden/restrictions of diabetes. Nurses focus on treatment of blood-glucose levels. main concerns patients: diet, fear of getting worse, damage caused by diabetes.
Koopman et al <i>the Netherlands</i>	2004	15 newly diagnosed pts diagnosis = < 6 mths	Observational study using interviews to assess manner of diagnosis and potential barriers to getting help	<i>Cognition:</i> 13/15 pts had experienced diabetes related symptoms but only 3 pts had recognized them as such. 7 pts still did not recognize their symptoms after diagnosis. Pts had a poor knowledge of diabetes even though 14/15 had relatives with diabetes.
Kasila et al <i>Finland</i>	2003	16 newly diagnosed pts diagnosis < 1 mth	Observational study analyzing initial counselling sessions with patients to determine their readiness for changing their dietary behavior. <i>Limits:</i> selective group at start of counseling.	<i>Behavior:</i> All pts recognized need for diet but less than half (7/16) were actively dieting. About one-third (6) were contemplating change. Three were making concrete plans to achieve their goals ( <i>preparation</i> ). One third (5) were actively changing their behaviour ( <i>action</i> ). 2 pts in <i>maintenance stage</i>

OBSERVATIONAL, RETROSPECTIVE, CATEGORY 3			
Beeney et al. <i>Australia</i>	1996 1159 diabetes pts, 785 type 2 pts 374 type-1 100 GPs diagnosis = ave 10 yrs	Observational study using questionnaires to assess concerns and information preferences at time of diagnosis. Compared with GP's perception of patients major concerns. <i>Limit:</i> no specific attention for newly diagnosed pts.	<i>Emotion:</i> 60% strong emotional reactions. 28% relieved. <i>Cognition:</i> Diet most often major concern at diagnosis (21%), followed by injections (15%), complications (13%) and lifestyle (13%). 20% had no concerns. GPs expect complications to be pts major concern. 80% of pts would have preferred more information and support.
Lo et al. <i>Australia</i>	2001 109 type-1 241 type 2 diagnosis = ave 4.2 yrs	Observational study. Questionnaires assess the coping trajectory of diabetes patients following diagnosis, including their pre-morbid lifestyle beliefs, perceived threat, coping responses and self care. <i>Limit:</i> Actual outcomes not reported, only relationships.	<i>Emotion and Cognition:</i> Impact of diagnosis greater for type 1 than type 2 pts. Type 2 pts more positive, more likely not to feel ill and need more time accepting diagnosis. Fear of consequences play a central role in patients reactions either resulting in negative emotions, or a positive focus to overcome challenges.
Dietrich <i>USA</i>	1996 7 type 2 patients diagnosis = 3wks-40yrs	Observational study. Interviews investigated the pts attitudes towards their illness and treatment. <i>Limit:</i> Selective and difficult recruitment. Small number. No attention for new pts.	<i>Emotion:</i> 6/7 had strong negative emotions at diagnosis. <i>Cognition:</i> Most considered diabetes a serious threat and feared loss of health and disease taking over one's life. Pts lack knowledge and had difficulty understanding info. A family history increased threat perception. Lack of symptoms and unclear messages by GP decreased threat and motivation to engage in self care.
Gillibrand et al. <i>UK</i>	2001 18 pts, 15 type 2 diagnosis = 2-52 yrs	Observational study using interviews to assess patient's perceptions of diabetes and its complications. <i>Limits</i> No differentiation newly diagnosed and long-term patients. Indicates responses w/o relative occurrence.	<i>Emotion:</i> All pts reported negative emotions at diagnosis. Anxiety only truly began when complications or treatment let patients experience the full implications of diabetes. <i>Cognition:</i> Major concerns were complications and lifestyle impact. Discussed knowledge, information provision and general responses to diagnosis.
Savoica et al., <i>USA</i>	2004 44 type 2 pts diagnosis > 1 yr	Observational study. Interviews contrasted experiences and attitudes of people at the extremes of control. <i>Limit:</i> Selective sample (poor Afro-americans)	<i>General:</i> Identifying 5 styles of adjustment to diagnosis (committed, tentative, hopeful, hassled and overwhelmed), related to good or poor control.
Hornsten et al <i>Sweden</i>	2004 44 pts diagnosis < 2 yrs	Observational study using interviews to assess pt's understanding of/ and experience of living with diabetes. <i>Limits:</i> a detailed description of variety of responses w/o indicating relative occurrence.	<i>Cognition:</i> Describes the personal understanding of illness among newly diagnosed pts, primarily stressing the variation along 6 themes, including image of the disease, its meaning, integration and space for illness in one's life, taking responsibility, and future prospects.

FOCUS GROUPS				
Author / country	Year	Type - # participants	Study design	Key result
Everett et al UK	1998	20 pts diagnosis < 6 mths	Focus groups examining impact of diagnosis	<i>Emotion:</i> All pts experienced process of bereavement <i>Cognition:</i> Pts had poor knowledge. Diet and injections major concern. Treatment with medication regarded as failure. Pts taking (more) medication perceived their diabetes to be more serious and less controllable.
Wenzel et al (2006) USA	2006	73 type 2 afroamerican diagnosis = ave 12 yrs	Focus groups assessing diagnosis experience Limit: selective sample Afro-americans	<i>Emotion:</i> Few patients shocked or surprised at diagnosis. Reaction related to symptoms, prior experience and treatment.

Abbreviations; diagnosis = time since diagnosis; wks = weeks; mths = months; yrs = years; pts = patients; GP = General practice

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