

What employees with diabetes mellitus need to cope at work: Views of employees and health professionals

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Abstract

Objective: To identify and compare patient and professional perspectives on what enables employees with diabetes mellitus (DM) to maintain their position in the workplace. To provide information on how professionals can help DM patients cope at work.

Methods: Qualitative study using concept-mapping sessions involving 23 employees with DM and 22 health professionals (GP's, occupational physicians and specialists). All of the health professionals were experts in the field of diabetes care.

Results: Patients and professionals identified five common clusters of statements on what diabetics need to enable them to cope at work: the ability to accept and cope with DM, supportive health professionals, a supportive work environment, work adaptations and good information. Patients emphasized the importance of emotional acceptance of DM and communication with colleagues, while the professionals emphasized the patient's capacity for self-care.

Conclusion: The content of patient and professional perspectives on what is needed to prevent work-related problems for DM patients differed slightly. Patients rely on direct experiences in their own environment, professionals on medical knowledge accumulated in groups of patients.

Practice implications: Both perspectives were used to suggest a topic list for health professionals, which may help identify and address the occupational problems experienced by DM patients.

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1. Introduction

Diabetes mellitus (DM) is a serious and increasing global health problem [1]. Despite improvements in diabetes care, the labor participation of people with diabetes is still lower than that of people without diabetes. The estimated work participation rate for individuals with diabetes is 62% between the ages 16 and 44 and 29% between the ages 45 and 64, in contrast to 77% and 50% for the general population in those age groups [2]. The increasing

prevalence and chronic nature of diabetes implies that continuity of care and self-management should be an important factor in the management of this disease.

Many of the activities that are needed to achieve glycemic control can be carried out by diabetics themselves, such as monitoring of blood glucose levels, medicating, dieting and exercise. For that reason, enhancing patients' capacities for the self-management of diabetes has become an important focus in current diabetes care [3]. Patient–professional communication is a crucial element of effective chronic illness care. However, effective communication is complex because professional and patient perspectives may differ [4].

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Current research has found that physicians and patients sometimes have different perspectives regarding the experience of having diabetes. For example, one study has found that continuity of care was perceived by patients to include a wider range of components than what is traditionally associated with continuity of care [5]. Another study found that patients experienced the effect of diabetes in a more psychosocial than physiological manner than clinicians perceived [6]. Two other studies confirmed that patients and professionals had differences in what they considered to be quality of care for patients with diabetes [7,8]. Recent studies have found that diabetes patients were not content with the education they received in support of social, experiential, ethical and financial aspects and about managing the illness at the time of diagnosis [9,10].

Current health policies in Europe promote the prevention of sickness absence and job loss among employees with chronic health conditions such as DM. Health care providers are in a good position to provide such support, because of their central role in diabetes care: they have the possibility to identify patients' work-related problems at an early stage and to offer appropriate information and support if needed. However, current clinical guidelines and treatment protocols for diabetes care and occupational health care provide little information on how health professionals may support patients in managing diabetes effectively at work. There are some generic instruments that may be useful in identifying work-related problems experienced by patients with chronic health conditions [11–13] but these instruments do not focus specifically on patients with diabetes. Furthermore, there is hardly any research on the effectiveness of interventions in this area [14].

Disability researchers have noted that the development of any intervention to improve the work situation of ill workers requires information about the direct experiences of the immediate stakeholders themselves, and especially the patients [15]. Previous studies on patient and professional perspectives on living with diabetes have not focused specifically on the patient's work situation. For that reason, the aim of this study was to explore and compare the ideas of employees with diabetes and health professionals with experience in diabetes or occupational health care as regards the kind of support diabetic patients may need in their work situation. The results were used as the basis for developing a topic list that may help professionals to identify the work-related problems experienced by diabetics and to support them in their work situation.

2. Methods

We used a qualitative research method, 'concept mapping', to collect information on the perspectives of employees with DM and health professionals on factors that may enable job retention. This method can be used in groups of between 20 and 25 individuals to elicit ideas from

individual members about complex issues and to map those ideas in a structured way at group level [16].

2.1. Participants

Purposeful sampling was used to select a group of up to 25 currently employed patients with diabetes mellitus and a group of up to 25 health professionals.

The inclusion criteria for employees were having been diagnosed by a doctor with diabetes mellitus type 1 or 2, being insulin dependent, having no other chronic illness which may affect work ability, having a paid job and being between 21 and 60 years old. Ninety-three patients who met the inclusion criteria for illness and age were selected at random by a diabetes consultant from the records of the diabetes outpatient clinic at the Academic Medical Center in Amsterdam (AMC). An invitation letter was sent to all the patients. Two weeks later, a researcher phoned 70 patients who had not responded to the invitation and checked if patients met the inclusion criteria for work. From the 70 patients, 50 patients could be contacted by phone. Finally, 25 patients who met the criteria for work and who were willing to participate in the study were accepted. All the participants signed an informed consent form before participating in the study. The non-response was mostly due to the fact that the concept-mapping session was held during the weekend and vacation time. The inclusion criterion for health care professionals was their experience in diabetes care. Participants were recruited through referrals from experts at the departments of internal medicine, general practice and occupational medicine of three university hospitals and the Dutch College of General Practitioners (NHG). Twenty-five professionals were invited to participate in the study. Twenty-two accepted the invitation. Three professionals did not complete a part of the assignment due to lack of time.

2.2. Data collection

Separate concept-mapping sessions took place for employees and professionals. A 4-h collective group session for the employees was held in September 2001 at AMC. The employees were first asked to generate statements completing the following sentence: "What a person with diabetes mellitus needs to be able to keep on working is ...". The concept-mapping method requires that statements do not contain multiple messages or are bound to time and place. Therefore, a facilitator encouraged the participants to clarify unfamiliar terms or jargon, and helped to edit the statements if needed. Each statement was typed into a computer by an assistant and printed on a card. Subsequently, each participant received a stack of cards with all statements. They were asked to rate the statements according to priority on a Likert scale (1 = lowest priority and 5 = highest priority). The participants then sorted the statements in a logical manner according to themes by forming clusters.

Each participant recorded the results of the priority rating and the theme sorting of the statements on a special form. These results were entered into the computer.

In the case of the professionals, no collective group session was held because they were not able to meet at the same time. Instead, the concept mapping took place by e-mail in March 2002. In a first round, each professional was asked to complete the aforementioned sentence with a maximum of 10 sentences. In a second round they were asked to prioritize and cluster the statements generated by the group in the same way as the employees, and to suggest names for the thematic clusters.

2.3. Data analysis

The statements generated by each group formed the basis of the data analysis. The analysis was performed using Ariadne, a computer program specifically designed to support concept mapping [17]. First, the arithmetical mean of the priorities the participants assigned to each statement was calculated. This resulted in a rating list of statements for each group. Second, a multidimensional scaling technique [18] was used to calculate, on the basis of a binary matrix, how often two statements were placed in the same theme or cluster by the participants. Based on sum scores for each statement a two-dimensional cluster map was drawn. The statements participants placed more frequently in the same cluster are located closer to each other on the map than those they grouped together less often. The employees were asked to discuss the results of the cluster map and give a name to each cluster. Since no group discussion was held with the health professionals, the research team selected an appropriate name for the clusters, based on the names the professionals had suggested by e-mail. Each cluster received a priority rating based on the priority ratings of the individual statements in the cluster (1 = low priority and 5 = high priority). To identify similarities and differences between employees and professionals, the clusters they produced were compared through content analysis. The study design was approved by the research ethics committee of the Academic Medical Center.

3. Results

3.1. Employees

Of the 25 patients who were invited to participate in the concept-mapping session, 23 showed up. Two were ill. The majority was well educated, did work that was mentally and physically demanding and had not altered their work situation after being diagnosed with diabetes (Table 1). Although being insulin dependent was an inclusion criterion, three of the participants were not using insulin at the time of the concept-mapping session. Despite this, we

Table 1
Characteristics of the participants in the concept-mapping session involving employees with diabetes mellitus ($n = 23$)

	Percentage
Female	48
Mean age	45 years (range 41–57)
Education level ^a	
Lower	23
Middle	55
High	22
Duration DM (years since first diagnosis)	
0–2	14
2–5	32
5–10	46
>10	8
Type of job ^b	
Light mental work	28
Heavy mental work	19
Mentally and physically demanding work	53
Work situation after diagnosis	
Has not changed	56
Working less hours a week	20
Changed type of job	24
Diabetes mellitus 1	46
Diabetes mellitus 2	54
Uses insulin	87

^a *Lower*: primary education and low level vocational training; *middle*: medium level secondary education; *high*: medium level vocational training to university.

^b *Light mental work*: administration, secretary, policy worker, application manager. *Heavy mental work*: laboratory technician, accountant, researcher, head of administration department, head of insurance company, head of trading company. *Mentally and physically demanding work*: driving instructor, aerobic teacher, nurse, freelance camera man, airplane mechanical controller, metro conductor, singing master.

decided to keep them in the study because they were patients at the outpatient clinic and could therefore be classed as relatively complicated cases.

These employees generated 54 statements in response to the question “What an employee with diabetes mellitus needs to be able to keep on working is . . .” and sorted these statements into eight clusters. Table 2 describes the clusters and the statements which were grouped, and the mean priority rating for each cluster and statement.

The statements in Cluster 1 indicated that both acceptance of the disease and a patient’s ability to cope with it was considered an important factor which allows people with diabetes mellitus to continue to work. Besides disease monitoring and control (blood glucose level), this also means that one should not be embarrassed about being a diabetic, accept the disease mentally, communicate about it with others and be determined to work. While Cluster 1 refers to more general coping abilities, Cluster 2 details what this implies at work. This includes such activities as taking one’s own food to work, having lunch at regular hours and not giving too much thought to the disease. Cluster 7 reflects

Table 2

What an employee with diabetes mellitus needs to be able to keep on working: clusters and the three most important statements per cluster generated by 23 employees with DM and mean priority scores

Cluster 1.	To accept and cope with diabetes (3.44): to maintain one's blood sugar level, to accept the illness, to try to live as normally as possible
Cluster 2.	To control diabetes at work (3.05): to take own food to work, to avoid thinking too much about diabetes at work, to have lunch at the same time each day
Cluster 3.	To inform colleagues and management about diabetes (3.24): to have colleagues that know how to react if you become unwell at work, to have colleagues who know you have diabetes, to inform colleagues about the possible complications of the illness
Cluster 4.	Adaptations at the workplace (3.05): to have a good balance between workload and the illness, to be able to rearrange and plan work at own pace, to have a stable work content and workload
Cluster 5.	Support and understanding from colleagues and management (2.64): to have colleagues who understand if you withdraw into yourself, to have a manager who knows what diabetes is, to avoid discrimination at job interviews, to talk to management about your daily condition
Cluster 6.	Support from health professionals (2.60): to have a supportive health professional, to have health professionals who can explain how to handle and prevent complications, to have health professionals at the company who know to react when there are complications
Cluster 7.	Information about technical devices and of ways to finance these (3.41): to receive financial aid to buy the necessary aids and devices, to talk to peers about diabetes to learn about the illness, to be assertive toward health professionals and management
Cluster 8.	Adequate benefits at work (2.27): to have adequate benefits at work

the importance attached to employees with diabetes having sufficient financial means to buy necessary aids and devices. They should also be assertive and well-informed about new aids and therapies and consult peers or patient organizations to learn from others how to deal with the disease. Having colleagues and managers who are aware that the employee has diabetes and who are educated about the complications of diabetes so that they know how to respond in case of an emergency, is considered another enabling condition for work (Cluster 3). Regular communication between the employee, colleagues and supervisors was perceived as an important means to create understanding (Clusters 3 and 5). Adaptations at work such as an appropriate workload were also considered relevant (Cluster 4). This includes the opportunity to plan work at one's own pace: flexible work schedules, a stable workload, opportunities for diabetes management at work and a relaxed atmosphere at the workplace. Support from health professionals was considered necessary (Cluster 6), particularly competent professionals with communication skills, even at the company, whose trust and information can make self-management of diabetes at work easier. Finally, adequate benefits at work (Cluster 8) were also considered necessary but to a limited extent (Fig. 1).

3.2. Health professionals

The group of professionals who participated in the concept-mapping session by e-mail consisted of 10 general practitioners, 6 occupational physicians, 4 specialists in internal medicine, 1 diabetes nurse and 1 human movement scientist. These 22 professionals completed the focus statement "What an employee with diabetes mellitus needs to be able to keep on working is . . ." with 75 statements. The respondents sorted these statements into six clusters (Table 3).

The professionals assigned the highest priority to the cluster 'competence for the self-management of diabetes' (Cluster 5). The statements in this cluster first express the idea that employees need to acquire sufficient knowledge and skills to regulate their blood sugar level, if necessary adapted to different circumstances. Next, they should be able to accept their illness, communicate about it with others and feel confident enough to work. Having a supportive family was also perceived as an enabling condition for work (Cluster 6). The third most important condition was support from health professionals (Cluster 2). They should tailor their interventions to the employee's work situation, be aware of the patients' working conditions and type of work,

Table 3

What an employee with diabetes mellitus needs to be able to keep on working: clusters and the three most important statements per cluster generated by 22 health professionals and mean priority scores

Cluster 1.	Work environment that permits disease management and work adaptations (3.09): the employee has the possibility to eat and to check his blood sugar level at the workplace as needed, the employee has enough time for self-care, it should be clear which tasks is a risk for diabetic employees
Cluster 2.	Support from health professionals (3.13): health professionals take the workload into account when the diabetic patient has problems in regulating his/her blood sugar level, health professionals have knowledge of the type of work the patient does and take this into account during treatment, the GP and specialist knows what type of work the patient does in order to coach the person effectively
Cluster 3.	Information and support aids (2.65): people with diabetes receive more information on diabetes in order to take good care of themselves, people with diabetes are encouraged to lead to a normal working life, more information about diabetes should be available to immigrants
Cluster 4.	Fair treatment of diabetics by society (2.87): there should be no discrimination when applying for a job, people with diabetes should have the same rights as healthy people, the employee can take good care of himself/herself and is not treated as a sick person
Cluster 5.	Competence in self-management of DM (3.73): to be able to regulate hypoglycemia on his/her own, to have the possibility to decide on his treatment schedule, to have enough knowledge about how to regulate one's blood sugar level, especially under different circumstances
Cluster 6.	Family support (3.41): the family encourages the person with diabetes to lead a normal life

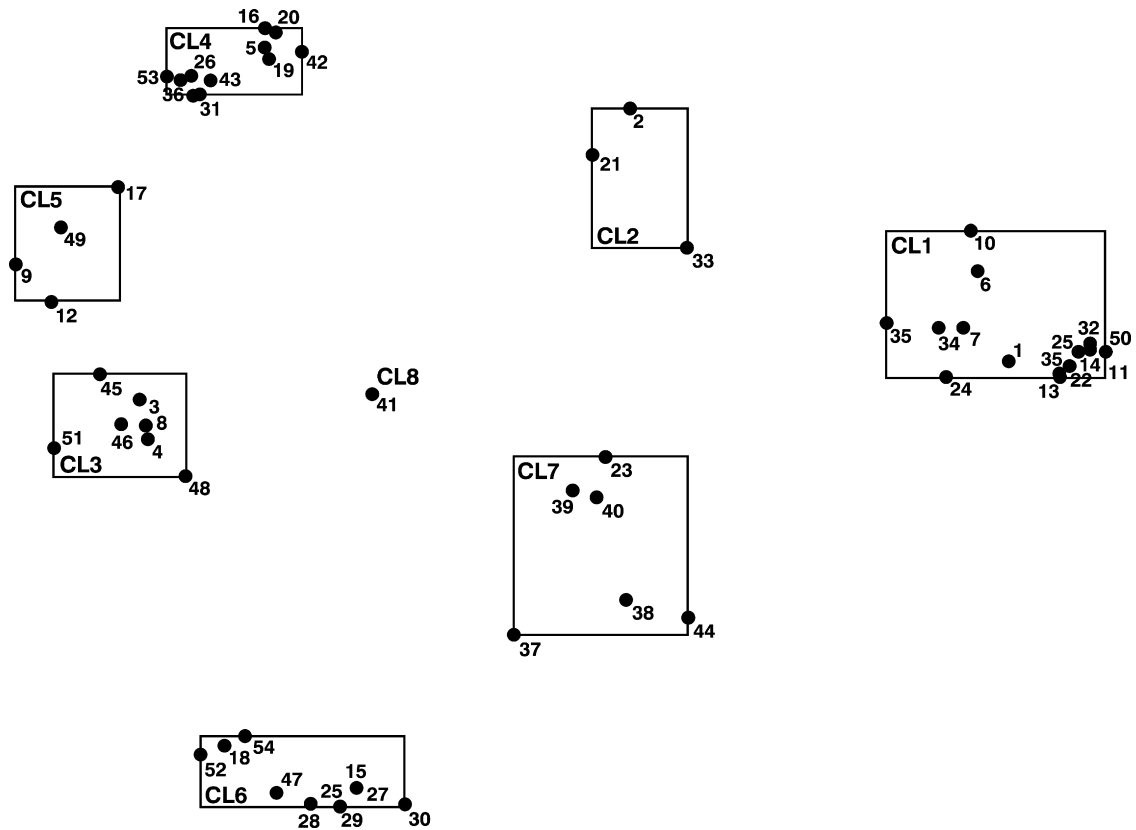


Fig. 1. Concept map of the employees with diabetes mellitus.

and encourage the patient to work. Joint support from occupational physicians, GPs and medical specialists was also considered useful. Interventions should be effective, simple and not be time-consuming. Furthermore, a work situation that allows for appropriate disease management and work adaptations was perceived as an important enabling factor for work (Cluster 1). In the eyes of the professionals, employees should have the opportunity to eat regularly and to control their blood sugar level as often as needed. Self-care may be facilitated by allowing employees to take some time off and by providing information about potential risks at work. Supervisors and colleagues should be aware of symptoms and be able to respond appropriately in hazardous situations. Searching for a balance between workload and capacities was considered important, specifically with regard working hours, night shifts, heavy physical work and lighting, while the presence of co-workers and supervisors who are well-informed about diabetes was also seen as an enabling factor for work continuation.

The professionals also thought that societal attitudes have an impact on work continuation (Cluster 4). Employees with diabetes mellitus should not be discriminated against when applying for a job: they should have the same rights as healthy applicants and should not be treated as ill. Finally, the statements in Cluster 3 indicate that more information

about the self-management of diabetes, especially to immigrants, may improve the diabetic's work situation (Fig. 2).

3.3. Comparison between the two groups

The employees and health professionals identified five common themes or conditions that may enable diabetics to carry on with their jobs: the ability to accept and cope with DM (Cluster 1 employees, Cluster 5 professionals); supportive health professionals (Cluster 6 employees, Cluster 2 professionals); a supportive work environment (Cluster 5 employees, Cluster 1 professionals); adequate working conditions (Cluster 4 employees, Cluster 1 professionals); enough information (Cluster 7 employees, Cluster 3 professionals).

Both groups assigned the highest priority to the cluster referring to an employee's ability to accept and cope with the disease. However, a comparison of the statements within those clusters shows that the two groups have slightly different ideas about what this means. Medical professionals emphasized that employees with DM should be competent and supported in the self-management of the physical symptoms of the disease, such as self-regulating one's blood sugar level. Six out of the 12 statements in Cluster 5 deal with this issue (Table 3). In contrast, employees assigned

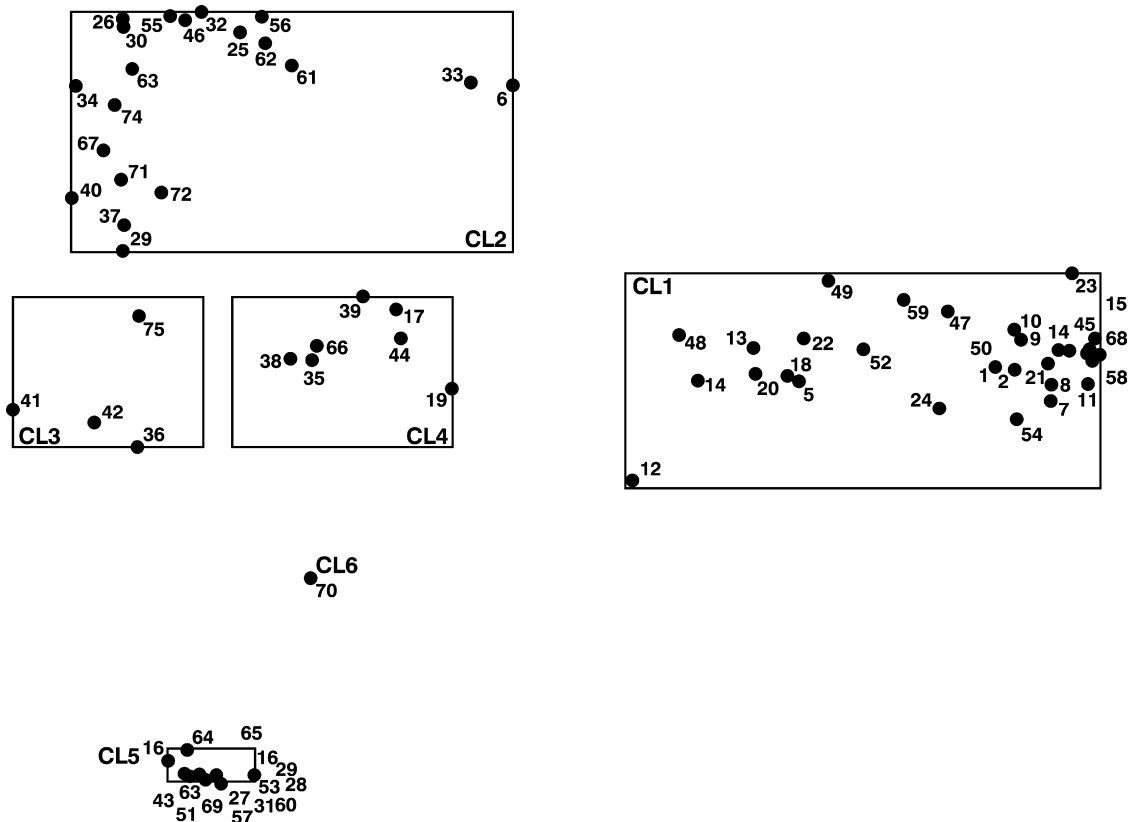


Fig. 2. Concept map of health professionals.

greater importance to the ability to cope with the disease emotionally and to accept it. Nine out of 14 statements in Cluster 1 refer to these issues (Table 2).

Interestingly, the second common theme ‘supportive health professionals’ had a higher priority for professionals than for patients, ranking third and seventh on their respective preference scales. A comparison of the statements in these clusters shows that, from the employees’ point of view, a supportive health professional is one who gives general support, who explains how to handle complications, who is accessible at the workplace and who adapts treatment to patients’ needs. In contrast, the professionals focused in particular on what professional support means in a technical sense: specific knowledge (e.g. about the type of work the patient does), specific interventions (e.g. coaching, encouraging, informing) and communication with colleagues from other disciplines.

A comparison of statements in the clusters referring to the third common theme ‘a supportive work environment’ also revealed some interesting variations. Employees rated understanding from management and colleagues (Clusters 3 and 5) slightly higher than the health professionals (Cluster 1), mentioning the communication with and support of colleagues more often. They gave a high priority (3.24) to colleagues who understand the effect of the illness on the employee and who can keep an eye on them.

Professionals mentioned more often that a supportive work environment should allow for self-management of diabetes.

Health professionals formulated more statements with respect to the fourth common theme ‘adequate working conditions’ and gave them higher priority scores. There are also some variations in the statements referring to the fifth common theme, ‘information’. Employees mentioned the need for information about technical support devices and financial support to purchase them. This did not feature among the professionals’ statements. However, the professionals referred to the importance of societal acceptance of people with diabetes and family support, while employees did not mention either of these topics.

4. Discussion and conclusion

4.1. Discussion

Prevention of frequent sickness absence and prevention of job loss for patients with DM is a new challenge in health care. In this study the method of concept mapping proved to be a useful method to elicit ideas from employees with DM and from health professionals as regards what employees with DM may need to prevent sickness absence and maintain

their position in the workplace. However, the method only allowed for the inclusion of a limited number of participants. Caution should therefore be exercised when generalizing on the basis of the results, as is the case for most qualitative methods [19,20]. Even though the concept-mapping method was used differently for patients and professionals we do not expect this to have influenced the results. The only difference is the influence of social group process at the time of generating statements. We think that patients are more influenced by the social group process than professionals.

This study has also shown that health professionals and patients have different perspectives regarding the needs of employees with diabetes mellitus. As medical sociologist Strauss [21] has shown, health professionals and patients are part of different social worlds and they use different interpretative frameworks to address problems. The former rely on accumulated medical knowledge about and experience with groups of patients and the latter on accumulated experiences in their own environment. This may be an underlying reason for variations in perspective between employees and professionals.

A noteworthy variation was that health professionals assigned greater importance to their own role in facilitating the work situation of employees with DM than the employees themselves. The employees regarded the support of health professionals as particularly relevant when there are major complications, but health professionals saw their task as much wider. Most of the employees in this study were chronic patients (>5 years). On the basis of their previous experience they may not have known they could consult health professionals for work-related problems.

4.2. Conclusion

Attention to social and emotional aspects of DM is a relatively new focus in diabetes care. In this study, different forms of concept mapping proved to be a useful method to elicit ideas from employees with DM and from health professionals on the needs of employees with diabetes mellitus to be able to continue working. The strength of the chosen method is that it builds on the direct experience of individuals who can be considered immediate stakeholders in the prevention of premature job loss among people with DM.

An interesting result is that the employees and professionals clustered the statements that were generated by their groups into five common themes referring to conditions which diabetics may need to cope at work: the ability to accept and cope with DM, supportive health professionals, a supportive work environment, work-adaptations and good information. A comparative analysis of the statements within those clusters revealed that the two groups differ in their perspective on the main requirements for meeting these conditions. For example, health professionals emphasized the importance of an employee's competence in the

technical self-management of DM, while the employees emphasized the importance of the individual's emotional acceptance of the disease.

In contrast to previous studies on patient and professional perspectives on diabetes, this study focused specifically on what working patients with DM need to continue their work. However, our results seem to underscore findings from a recent study by Kalpana et al. [5]. This study found that physicians who were knowledgeable and attentive to patient needs (like access to clinical services and financial support), stayed current with developments in diabetes care and paid attention to the feeling of self responsibility of patients were most appreciated by patients.

4.3. Practice implications

At present there are only a few generic instruments which may be used to identify the work-related problems of people with chronic health conditions. There is a lack of specific instruments focused on patients with DM. We have used the five common themes which were identified by professionals and employees, as the basis for a topic list that may be useful for health professionals who want to identify and address work-related problems faced by patients with DM (Appendix A). Of course, this list is only provisional and needs to be evaluated further in practice and through research.

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Appendix A

1. *Acceptance*: As a diabetic, how are you able to cope at work?
2. *Disease management at work*: Do you have a regular self-care schedule at work? Are there any obstacles at work that prevent you from carrying out your self-care schedule?
3. *Work adaptations*: Do you think any adaptations are needed at work which may improve your well-being?
4. *Communication with manager and colleagues*: Have you informed your manager and colleagues that you have DM? Are your manager and your immediate colleagues well-informed about diabetes and the possible complications of the disease? Does your manager and your immediate colleagues know how to react if there are any complications? Are you able to discuss any work adaptations you may need with the people responsible at work?
5. *Information*: Do you feel you have sufficient information on how to deal with diabetes at work? Do you have sufficient information about aids and equipment for self-care of diabetes that may be useful at work? Does the management of diabetes at work entail extra expenses? Are you compensated for these extra expenses?
6. *Health professionals*: Would you appreciate any specific support for your work situation from health professionals?

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