

Resources for and barriers to effective diabetes care management - experiences and perspectives of people with type 2 diabetes

Hasseler, Martina K.; Heide, Marco; Indefrey, Sonja

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Title: Resources and barriers of an effective diabetes care management - experiences and perspectives of people with type 2 diabetes

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Corresponding Author: Prof. Dr. Martina Karola Hasseler, Ph.D

Corresponding Author's Institution: University of Applied Sciences Hamburg

First Author: Martina Karola Hasseler, Ph.D

Order of Authors: Martina Karola Hasseler, Ph.D; Marco von der Heide, Dipl.- Pflegelehrer, Staatsexamen Pflegewissenschaft; Sonja Indefrey, Dipl.- Pflegelehrer, Staatsexamen Pflegewissenschaft

Abstract: Aims: To identify barriers and resources of an effective diabetes care management from the perspectives of patients with diabetes.

Background: The current health care situation of patients with diabetes indicates that the German health care system is not sufficiently prepared for the increasing incidence rate.

Methods: Qualitative design reflecting symbolic interactionism as a methodological background.

Problem-centered interviews were used for data collection. A qualitative content analysis was applied for data analysis.

Results: Findings suggest a need for individual- and resource-oriented concepts of care in home settings. Participants rate exercise, professional and social support as well as self-efficacy as important resources in diabetes management. Barriers such as lacking acceptance of the disease, problems in adjustment to a new diet as well as utilisation of diabetes education in the daily routine, cognitive impairment and impaired perception of physical changes such as neuropathy, were identified.

Conclusions: Prevention orientated counselling and education concepts in diabetes management should systematically integrate the resources of patients with diabetes and tackle the barriers they perceive in order to support them in their specific care needs.

Response to Reviewers: Dear Sir or Madam,

Thank you very much for revising my manuscripts. The comments and suggestions are very helpful to improve this manuscripts. I revised my manuscript as recommended:

1. Native speaker: A native speaker from UK revised the manuscript thoroughly.
2. Abstract: I deleted the German abstract.
3. Background: Questions: I reformulated question 1: 1. How do patients with diabetes cope with the disease with regard to their health/disease-related behaviour?
4. Methodology: I followed the suggestions of the reviewer and deleted the blank before the comma.
5. Results and Discussion: I followed the suggestions of the reviewer and corrected line 9 and line 12.
6. Results and Discussion: I followed the suggestions of the reviewer and corrected line 14 and 44.

7. Methodology: I corrected Methodology in Methods. Furthermore, I added a paragraph on following information: when was study carried out, socio-demographic characteristics of the sample and sampling

"As part of the inclusion criteria for this project, individuals had to be over the age of 50, diagnosed with type II diabetes for at least 2 years, able to give informed consent, able to understand and speak German fluently and living inside or around a city in the north of Germany. Participants were recruited over a period of three months from March 2008 until May 2008. The process of recruiting was carried out at GP (General Practitioner) surgeries and diabetes support groups. Overall, a convenience sample was drawn and seven patients with type 2 diabetes willing to participate in the study were interviewed. Overall, five female and two male diabetics between 55 and 76 years were interviewed. Three of the participants were married, one was single and three were widowed. All of them learned a profession but six were retired with only one still working in his profession. The income level ranged between 500 € and 1.500 € monthly."

8. Conclusion: I added information on limitations of the study and future proceedings:

See page 3: The findings of the project form the basis for developing a nurse-led diabetes care management program in primary care settings in Germany. The aim of the further project is an individual-centered concept of care which considers the resources as well as the daily difficulties of patients and attempts to develop need-orientated solutions in co-operation with the patients in order to enhance permanent changes in life-style and disease-related behaviour. The design and structure of the nurse-led diabetes clinics follows a preventative home visit approach with regular home visits. Therefore, the perspective of patients with type 2 diabetes is of high importance. For that reason, a qualitative and explorative design based on symbolic interactionism was chosen. This approach enables to explain the subjective behaviour as well as people's consciousness of social processes [14].
See page 10: "Since only seven diabetics were interviewed the validity and reliability of the results are limited. However, they indicate that diabetes management programs need revisions and more person-centered and health promotional approaches. For that reason, more research is required to gain further insight into the perspectives of people concerned in order to integrate these findings into more effective diabetes management programs. It is planned to develop on the basis of the findings a more standardised questionnaire for people with type 2 diabetes and to examine their perspectives of useful and meaningful diabetes counselling and management. Furthermore, the findings of the project form the basis for developing a nurse-led diabetes care management program in primary care settings in Germany as described above."

Yours sincerely

Resources and barriers of an effective diabetes care management – experiences and perspectives of people with type 2 diabetes

Ressourcen und Barrieren für ein effektives Diabetesmanagement – Erfahrungen und Perspektiven von Personen mit Diabetes Typ 2

Korrespondenzautor

Prof. Dr. Martina Hasseler,

HAW Hamburg (z. Zt. beurlaubt)

Fakultät Wirtschaft & Soziales

Pflegewissenschaft

Saarlandstr. 30

22303 Hamburg

Marco von der Heide, Dipl.- Pflegelehrer, 1. Staatsexamen Pflegewissenschaft, Universität Osnabrück

Sonja Indefrey, Dipl.-Pflegelehrerin, 1. Staatsexamen Pflegewissenschaft, Universität Osnabrück

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Resources and barriers of an effective diabetes care management – experiences and perspectives of people with type 2 diabetes

Abstract

Aims: To identify barriers and resources of an effective diabetes care management from the perspectives of patients with diabetes.

Background: The current health care situation of patients with diabetes indicates that the German health care system is not sufficiently prepared for the increasing incidence rate.

Methods: Qualitative design reflecting symbolic interactionism as a methodological background. Problem-centered interviews were used for data collection. A qualitative content analysis was applied for data analysis.

Results: Findings suggest a need for individual- and resource-oriented concepts of care in home settings. Participants rate exercise, professional and social support as well as self-efficacy as important resources in diabetes management. Barriers such as lacking acceptance of the disease, problems in adjustment to a new diet as well as utilisation of diabetes education in the daily routine, cognitive impairment and impaired perception of physical changes such as neuropathy, were identified.

Conclusions: Prevention orientated counseling and education concepts in diabetes management should systematically integrate the resources of patients with diabetes and tackle the barriers they perceive in order to support them in their specific care needs.

Keywords: diabetes management, nurse-led diabetes clinic, primary care, prevention, health promotion

Background

At present, approximately 6 million people in Germany have a diagnosis of type 2 diabetes. The prevalence rate is increasing with the current rate being 5% a year. The health care costs for patients with diabetes mellitus type 2 place a financial pressure on the German health care system costing approximately 16 billions Euros a year. The majority of the money is allocated to treat the long-term effects of diabetes and related complications (Liebl et al. 2001; Lange et al. 2002). However, the prevalence rate increases in lower socioeconomic levels, the reasons for which are manifold. In lower socioeconomic levels more risk factors can be identified such as obesity or level of education, which are linked to health-related behavior as well as inadequate utilization of health care measurements (Brown et al. 2004). Furthermore, research indicates that people with a lower education level participate less in preventative measures, health-related education and training programs (Mielck and Helmert 2006). In light of these developments, health care concepts and programs for patients with type 2 diabetes face new challenges.

Effective diabetes care management programs aim at changing the life-style of those concerned. Beneficial factors for a permanent change of life-style are support networks as well as on-going diabetes- relating counseling, education and training programs (NAFDM 2006; Hasseler and Remmers 2007). Research findings in public health indicate that measurements for behaviour modification are more effective in terms of scope and consistency if they are well integrated in the circumstances, social environment and mode of life of those concerned. Especially, measurements following a setting-oriented approach are considered much more effective (Rosenbrock and Gerlinger 2004). The health care situation of patients with type 2 diabetes is viewed as problematic in the primary care setting in Germany. The workload as well as time pressure in primary care has increased considerably within the last years. Studies reveal that diabetes care management is in many cases uncoordinated, integrated health care concepts are absent and patients rarely receive a systematic consultation and education (Gabbay et al. 2006; Möller et al. 2004; Taylor et al. 2005). Social, psychological and biographical aspects of the lives of diabetics are infrequently taken into consideration. Current education and training modules for patients with type 2 diabetes are focused on a traditional concept of teaching and education with an aim of mere knowledge transfer without considering individual circumstances. An individual- and setting-orientated concept of diabetes management in primary care is missing, even though the majority of diabetics are cared for in the primary care setting (DDU/NAFDM 2007; Hasseler and Remmers 2007; NAFDM 2006).

The objective of the project was to identify diabetes-related coping strategies and problems of adjustment to the disease from the perspective of patients suffering from diabetes in order to reveal needs for support with their daily routine and life in general. In particular, barriers and facilitators or resources which enhance or hamper an adjustment to health-related behavior were of interest in this project.

Against this background following research question were formulated:

1. How do patients with diabetes cope with the disease with regard to their health/disease-related behaviour?
2. Which resources do patients with type 2 diabetes use? What meanings have the resources in order to implement a healthy behavior and lifestyle?

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4 3. What are the barriers hindering the implementation of a healthy behavior and lifestyle
5 in patients with type 2 diabetes?
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8 The findings of the project form the basis for developing a nurse-led diabetes care management
9 program in primary care settings in Germany. The aim of the further project is an individual-
10 centered concept of care which considers the resources as well as the daily difficulties of patients
11 and attempts to develop need-orientated solutions in co-operation with the patients in order to
12 enhance permanent changes in life-style and disease-related behavior. The design and structure of
13 the nurse-led diabetes clinics follows a preventative home visit approach with regular home
14 visits. Therefore, the perspective of patients with type 2 diabetes is of high importance. For that
15 reason, a qualitative and explorative design based on symbolic interactionism was chosen. This
16 approach enables to explain the subjective behavior as well as people's consciousness of social
17 processes (Lamnek 2005).
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23 **Methods**

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25 Problem-centered interviews according to Witzel (2000) were used for data collection. This tool
26 includes a short questionnaire on socio-demographic data such as age, gender,
27 profession/occupation, qualification and year of diabetes diagnosis. Furthermore an interview
28 guide with open-ended questions was used to ensure that certain information was collected. The
29 questions were focused on lifestyle, experiences in daily life, support measures, experiences with
30 health professionals, social support, important resources. The inductive-deductive approach of
31 this data collection tool ensures to understand individual and subjective actions and meanings of
32 actions as well as social reality in the interpretation of the individuals (Mayring 1990; Witzel
33 2000).
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37 The interviews were tape-recorded and transcribed verbatim. A qualitative content analysis was
38 applied for data analysis in order to identify major themes from the data (Mayring 1990).
39 According to rules and theoretical principles a coding system was developed. The interviews
40 were structured, paraphrased, categorized as well as analyzed on the basis of the coding system.
41 Overall, 12 main categories could be developed: 1. well-being/satisfaction, 2. individual concepts
42 of disease and experience of disease, 3. life-style, 4. education/knowledge, 5. physical perception
43 , 6. individual coping strategies, 7. monitoring, 8. social support, 9. family life, 10.
44 religion/spirituality, 11. social life, 12. health care.
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48 As part of the inclusion criteria for this project, individuals had to be over the age of 50,
49 diagnosed with type II diabetes for at least 2 years, able to give informed consent, able to
50 understand and speak German fluently and living inside or around a city in the north of Germany.
51 Participants were recruited over a period of three months from March 2008 until May 2008. The
52 process of recruiting was carried out at GP (General Practitioner) surgeries and diabetes support
53 groups. Overall, a convenience sample was drawn and seven patients with type 2 diabetes willing
54 to participate in the study were interviewed. Overall, five female and two male diabetics between
55 55 and 76 years were interviewed. Three of the participants were married, one was single and
56 three were widowed. All of them learned a profession but six were retired with only one still
57 working in his profession. The income level ranged between 500 € and 1.500 € monthly.
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Results and Discussion

The starting point of this project was to question how patients with diabetes view and perceive resources, barriers and support in order to change and to adjust life-style and health-related behavior. In summary, patients with type 2 diabetes apply a variety of coping styles. The necessary implementation of changes of life-style and health-related behavior causes challenges in the daily lives of these patients. The most important categories and discussions are presented below.

Well-being and satisfaction

The study participants have been diagnosed with type 2 diabetes for several years. In retrospect they conclude that subjective satisfaction and well-being have not changed since being diagnosed with diabetes. They perceive variation in blood sugar levels as unpleasant but it does not influence their subjective satisfaction and well-being. All of the interviewed participants state that they do not follow a strict diet in order to enhance their subjective satisfaction. An enhancement of subjective satisfaction and well-being is associated with improved physical activity and mobility. A decrease in subjective satisfaction and well-being is attributed to diabetes-related complications or general uncertainty about how to handle the disease. The participants perceive physical restraints as an important reason for less satisfaction and well-being. They refer particularly to physical restrictions and pain as important factors influencing their performance of daily activities.

It seems that with regard to subjective well-being and satisfaction the disease is only of secondary concern. It becomes obvious, as Schneider et al pointed out (Schneider et al. 1999), that the disease influences the subjective well-being and satisfaction only to a minor degree.

On one hand, the results suggest that diabetics have integrated the disease in their life. It seems that they have obtained an insight into the disease as well as treatment which results in an acceptance of the chronic disease, an increased diabetes-specific knowledge and an active participation in therapy and treatment. On the other hand, the results could implicate that they have a low insight into the disease and treatment as they perceive diabetes only of secondary influence to their live, satisfaction and well-being. It is possible that diabetes-related knowledge is not applied appropriately to their lives and that consistent diabetes treatment and life-style are not adhered to. This could result in diabetes-related complications which could negatively influence satisfaction and well-being (Woods-Büggeln 2002). A lack of acceptance of the disease could constitute a barrier to follow a healthy life-style and behavior. A specific need for support for patients with type 2 diabetes emerges from these findings. Diabetes clinics that are focused on a preventative and health promotional approach, aiming to empower patients and supporting them in their self-management should assist diabetics in developing an improved and encompassing awareness of the disease as well as insight into the disease.

Individual concepts of disease and experience of disease

This category is focused on the question how people explain and how they experience their disease. Health- and disease-related behavior is subjected to different determinants, e.g. for instance subjective theories of diseases, which are of importance for disease-related behavior and

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4 physical perception. People suffering from a disease are generally prepared to change harmful
5 behavior when they are of the opinion that they can positively influence the course of disease and
6 the outcomes. Harmful health-related behavior will be maintained or cultivated if it appears that
7 the onset and progression of the disease can not be influenced, e.g. due to genetic pre-disposition
8 or 'fate' (Fürstler and Hausmann 2000).
9

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11 The participants in this project offer different subjective concepts of diseases. Genetic heredity
12 was the most mentioned concept.
13

14 In addition to that some participants are of the opinion that other diseases have triggered the
15 disease or that deep emotional experiences have caused it.
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18 With the exception of the genetic pre-disposition as a causal explanation factor for type 2
19 diabetes (Kerner et al. 2001) no other references in the literature relating to the expressed
20 individual concepts of disease could be found.
21

22 In summary, these results show that the participants have limited knowledge about diabetes with
23 regards to pathophysiology and aetiology. For that reason, they tend to apply a laypersons'
24 concept. This could indicate a lack of insight into the disease and a need for increased support in
25 order to improve an awareness of the disease as well as related side-effects, complications and
26 necessary changes of life-style.
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29 **Life-Style**

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31 The category "life-style" includes the sub-categories diet, physical activity and daily routine. The
32 most significant changes have occurred within the **sub-category "diet"**. Most of the participants
33 consider the adjustment to a new diet as very difficult. Only after many years of adaptation to it,
34 the diet is not longer regarded as problematic and is integrated into the life style of the
35 participant. Kulzer & Hermanns (1995) have also referred to the process of internalization of new
36 diets for people with diabetes which obviously takes a longer period of time. Furthermore, the
37 data suggest a gender difference with regards to knowledge about a diabetes adjusted diet. For
38 instance, the female diabetics demonstrated a differentiated knowledge and revealed recipes in
39 the interviews. On the contrary, the male diabetics have made no specific comments on the new
40 diets.
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44 This finding suggests that female and male diabetics have different needs in teaching, education
45 and information. Gender could influence the adjustment and adaptation to different aspects of
46 diabetes-related life-style and the outcomes of diabetes clinics. The role of gender needs further
47 consideration and research in how to develop effective diabetes clinics and consultations.
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50 Another very interesting finding is related to insulin. Some of the participants use insulin
51 purposefully in order to compensate for maladaptive eating patterns that are not in keeping with
52 the diet, as it allows quick adjustment of blood sugar levels.
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55 Literature suggests that the use of insulin liberalizes diabetes management and therapy which
56 facilitates individual autonomy (Chantelau 1995). The reclamation of autonomy can be regarded
57 as positive in diabetes management and therapy however; it carries the inherent danger that
58 necessary adjustments in diet are not taken seriously, which make a relapse into previous eating
59 patterns and behavior more likely. On the basis of this finding, it can be concluded that patients
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4 with type 2 diabetes receiving a medication-based therapy need special support and counseling
5 which stresses the importance of behavior- and life-style modification (Seidl et al. 2007).
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8 With regards to the **sub-category physical activity** it can be summarized that all participants
9 engage in physical activity and consider it as very important for their diabetes management and
10 disease-related quality of life. Physical restraints are regarded as negative and they can result in
11 restrictions on daily activities as well as social contacts. On the other hand, increased physical
12 activity causes wellbeing and higher quality of life. The importance and effects of physical
13 activity coincides with guidelines on evidence-based diabetes management (Hader et al. 2004).
14

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16 The findings in **sub-category changes in daily routine** indicate that activities in the daily routine
17 are planned well ahead according to the diabetes therapy.
18

19 According to the „health-belief-model“ (Schwarzer 1996) people with a lack in awareness of
20 problems are less prone to change their health behavior compared with people with a higher
21 awareness of problems who actively try to influence their situation. Thereby, self-efficacy plays
22 an important role in adjusting and adapting the daily routine. It mirrors the expectation that
23 human-beings possess the necessary competencies and are able to use them adequately in order to
24 deal and cope with certain situations (Vogt 2006). The collected data display the important
25 significance of self-efficacy in self- management. A lacking disease-related awareness of
26 problems and a low self-efficacy hampers modification of behavior.
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29 **Education and knowledge**

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32 Special training courses for diabetics represent an important part in coping with the disease.
33 Overall, the participants felt well informed about the disease after participating in a training
34 course.
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36 However, in retrospect and compared with previous results it is obvious that the study
37 participants show deficits in diabetes specific knowledge which lead to the conclusion that
38 special training courses do not result in the desired outcomes.
39

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41 All participants reported positive as well as negative aspects of the special training courses they
42 attended. They rated new knowledge about diet and open discussion of the disease as positive.
43 Furthermore, they appreciated group sessions and the opportunity to talk to other diabetics about
44 the disease. From the perspective of the participants, individual training courses were perceived
45 as positive when individual problems needed solving. In summary, special training courses can
46 be regarded as social resources in order to integrate diabetes in the daily routine.
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49 The negative aspects of special training courses referred to difficulties in transferring contents of
50 the training courses into daily life. Modifications of behavior are hampered by these difficulties.
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53 Despite the fact that most participants attended the courses several times it becomes obvious that
54 they have deficits in diabetes self-management.
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56 Overall, the data suggest that traditional diabetes training courses only offer solutions to the
57 problems of coping with a disease to a certain degree. New concepts of education and counseling
58 have to be developed, which follow the strategy and objective to support patients with diabetes in
59 their daily routines.
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4 Some interviews give the impression that cognitive impairment leads to difficulties in applying
5 new knowledge to the daily routine. In addition, individual barriers such as lack of motivation
6 can hamper the application of new knowledge in the daily routine.
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9 The application of contents and knowledge of training courses decreases with increased therapy
10 requirements. Furthermore, intervention and therapy measurements are less often transferred into
11 daily lives when they require a higher level of self-control. Since the sample in this project
12 includes mostly elderly participants it can be concluded that impairment of cognitive skills and
13 competencies represent a barrier in the adequate application and implementation of new
14 knowledge to the lives of those concerned (Lange et al. 2002).
15

16
17 Most of the participants were of the opinion that the inclusion of families in the training courses
18 would be very helpful. As one participant pointed out:
19

20 It seems to be important that families receive the same information as the diabetics in order to
21 enable them to understand the disease and the necessary interventions and measurements. On the
22 basis of this finding it can be concluded that families represents a very important social resource
23 which needs to be included in education, training and counseling.
24

25 26 **Physical perception**

27
28 The study participants notice physical changes, especially obesity, hypoglycaemia or co-
29 morbidities as a result of the diabetes.
30

31 Nevertheless, it seems to be more difficult for them to sense complications such as neuropathy.
32 Only one participant educated herself explicitly about possible complications and she elaborated
33 the information in the interview. The other interviewees did not offer much information on this
34 specific topic. Compared with data analyzed from the short questionnaire it can be assumed that
35 the participants either play the effects, risks and complications of diabetes down or the perception
36 of risks and complications in diabetes is not very well developed. It becomes evident that future
37 consultations and clinics in diabetes care should integrate physical changes and complications of
38 diabetes.
39
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41 42 **Social support**

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44 According to Kuzla the understanding of social support occurs on emotional and spiritual as well
45 as instrumental and physical/practical levels (Fürstler and Hausmann 2000).
46

47 These data suggest that the participants in this study received social support from different
48 sources. Family represents the most important source. The interviewees viewed support from
49 their families as positive and individualised. Family support seems to be much more directed at
50 emotional and physical/practical levels. Especially support in coping with the diseases,
51 uncertainties in detecting symptoms and changes in diet were raised.
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54 Besides the individuals' families, support groups were rated as an important source of support.
55 They offer spiritual and instrumental support in particular and enable diabetics to talk about their
56 diseases and to get reassurance.
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4 The data gives the impression that support groups assist the participants to shed their role as a
5 chronically ill patient and thus to regain a normal everyday routine. Participation in self-help
6 groups could contribute to support self-management and represents that therefore a very
7 important resource of social support (Petermann and Wendt 1995).
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10 Health care professionals offer a predominantly instrumental assistance in the process of social
11 support.
12

13 It is of high importance for diabetics to have access to diabetes-related knowledge. The first port
14 of contact is usually their GP (General Practitioner) or clinical based diabetes adviser. These
15 finding mirrors the current health care situation for people with diabetes in Germany. Generally,
16 GPs (General Practitioner) treat and counsel diabetics in their practices in primary care settings.
17 In addition, diabetes-specialized surgeries offer diabetes management and therapy. Each
18 specialized practice treats up to 400 people with diabetes (Deutsche Diabetes Union 2006;
19 Gesundheitsziele.de. Forum für Gesundheitsziele Deutschland 2003; Möller et al. 2004).
20 However, due to the high amount of people suffering from diabetes in Germany and the high
21 workloads of GPs (General Practitioner) and diabetes specialists, individual-centered counseling
22 is hardly feasible (Gabbay et al. 2006; Taylor et al. 2005; Möller et al. 2004). Based on these
23 findings, nurse-led diabetes clinics within the primary care setting following a regular
24 preventative home visit concept could improve the access to health care and patient-centred
25 consultations. It could furthermore provide the integration of the family in the consultation
26 process which is not possible in GP surgeries (General Practitioner) or specialist practices. A
27 recent report on diabetes in Germany stresses the significance of health professionals working
28 with diabetics to strengthen their efforts to support people suffering from diabetes
29 (DDU/NAFDM 2007). Obviously, the traditional structures and infrastructures of diabetes
30 therapy and management are not sufficient and effective in Germany`s primary care setting.
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36 **Health Care**

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38 For the category health care three subcategories were formed: **helpful interventions** and
39 **measurements, unnecessary interventions and measurements, wishes/demands.**
40

- 41 • Generally, satisfaction with medical care seems to be high. The participants value
42 particularly the care they received in diabetes-specialized hospitals **as very helpful.**
- 43
44 • However, they very often perceive compulsory **interventions and measurements**
45 **as unnecessary.** In particular if these are prescribed and the participants can not decide
46 independently if they want to obtain them or not. Another disadvantage seems to be a lack of
47 information with regard to the health system. On one hand, the interviewees point to services
48 offered by health care insurances which are not transparent to them. On the other hand, they are
49 only aware of training courses as diabetes-relevant health care services.
- 50
51 • Concerning the **sub-category requests and demands for the health system** they
52 require more preventative interventions and measurements which have the potential to support
53 them in coping with the disease and to offer those regularly.
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4 It has to be taken into consideration that it is a difficult task to measure satisfaction in health care.
5 Especially, if those concerned do not receive enough information about measurements and
6 interventions. However, the data give the impression that there is a lack in individual-focused and
7 preventative orientated measurements and initiatives for patients with type 2 diabetes in
8 Germany. Furthermore, the finding that some of the participants have felt some measurements
9 and interventions as obligatory needs to be to be critically discussed. Taking into consideration
10 that some participants perceive difficulties in self-management and a need for more information
11 and preventative measures, it can be concluded that so far the measurements and interventions in
12 diabetes care management are not effective and do not fulfill the needs of patients with diabetes.
13 Subjective ideas about health, disease, depression etc., influence the self-management of these
14 patients. Empowering people and supporting them in their needs is time-consuming. Due to high
15 workloads and economic pressures GP's (General Practitioners) and specialists in private
16 practices very often lack time to offer individual-centered, comprehensive discussions,
17 consultations and instructions for the clients and their families (Gabbay et al. 2006; Taylor et al.
18 2005; Möller et al. 2004).

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23 In the light of theories in health promotion and the necessity of empowerment it is questionable
24 whether the current approach in diabetes care management in primary care settings in Germany is
25 effective. In order to achieve sustainable effects in education, training, instruction and counseling
26 in diabetes care, it is imperative to introduce integrative models of care which take the
27 knowledge, expectations, feeling of well-being of those concerned into consideration (Hirsch
28 2002). These concepts of care should support empowerment and self-management of diabetics.
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31 **Conclusion**

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34 The results indicate that people with type 2 diabetes need support in the primary care and home
35 setting. The current services in the German health system do not fulfill the needs of patients with
36 diabetes to receive individual-centered care, family integration as well as comprehensive
37 consultations, counseling and instructions.
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40 The support needs to be focused on knowledge application, modification of disease-and health-
41 related behavior as well as assistance in dealing with daily difficulties. Furthermore it needs to
42 address challenges and perception of physical changes and complications due to diabetes. Besides
43 a special diabetes-related knowledge and resources are of high importance for these patients in
44 order to cope with the disease in their day-to-day life. The integration of families in consultations
45 or training courses could be valuable in the diabetes care management process. Families represent
46 very important social resources and could support diabetics in their efforts to change life-style
47 and health-related behavior. The extracted data suggest that diabetes clinics need a gender
48 oriented approach. Women and men suffering from diabetes deal differently with the disease and
49 take different approaches. Health professionals could support people with diabetes coping with
50 the disease by applying the resources and reducing the barriers perceived by patients. It is of high
51 importance to strengthen the responsibility and the autonomy of patients with diabetes in order to
52 enhance diabetes self-management and diabetes-related quality of life. In addition, research has
53 shown that nurse-led clinics can be an effective concept of care in primary and in partnership
54 with GPs (General Practitioner) for people suffering from type 2 diabetes (Gabbay et al. 2006;
55 Taylor et al. 2005; Wong and Chung 2006). Since only seven diabetics were interviewed the
56 validity and reliability of the results are limited. However, they indicate that diabetes
57 management programs need revisions and more person-centered and health promotional
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4 approaches. For that reason, more research is required to gain further insight into the perspectives
5 of people concerned in order to integrate these findings into more effective diabetes management
6 programs. It is planned to develop on the basis of the findings a more standardized questionnaire
7 for people with type 2 diabetes and to examine their perspectives of useful and meaningful
8 diabetes counseling and management. Furthermore, the findings of the project form the basis for
9 developing a nurse-led diabetes care management program in primary care settings in Germany
10 as described above.
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19

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24 **References**

- 25
26 Brown AE et al (2004) Socioeconomic position and health among persons with diabetes
27 mellitus: a conceptual framework and review of the literature. *Epidemiologic Reviews*
28 26:63-77
29
30
31 Chantelau E-A (1995) Diät bei Diabetes mellitus. In: Berger M (ed) *Diabetes mellitus*. Urban &
32 Schwarzenberg Verlag München, Wien, Baltimore, pp 26-158
33
34 DDU/NAFDM (2007) *Deutsche Diabetes Union und Nationales Aktionsforum Diabetes*
35 *mellitus: Deutscher Gesundheitsbericht*. Diabetes 2008, München
36
37 Deutsche Diabetes Union (DDU) (2006) *Deutscher Gesundheitsbericht. Die Bestandsaufnahme.*
38 *Diabetes 2006*, München
39
40 Fitzgerald Miller J (2003) *Coping fördern – Machtlosigkeit überwinden. Hilfen zur*
41 *Bewältigung chronischen Krankseins*. Hans Huber Verlag, Bern, Göttingen, Toronto,
42 Seattle
43
44
45 Fürstler G, Hausmann C (2000) *Psychologie und Sozialwissenschaften für Pflegeberufe 2,*
46 *Klinische Psychologie, Behinderung, Soziologie*. Facultas-Universitätsverlag, Wien
47
48 Gabbay RA et al (2006) Nurse case management improves blood pressure, emotional distress
49 and diabetes complication screening. *Diabetes Research and Clinical Practice* 71: 28-35
50
51
52 Gesundheitsziele.de. Forum für Gesundheitsziele Deutschland (2003) *Bericht. Auszug der*
53 *Ergebnisse AG 4. Diabetes mellitus Typ 2. Erkrankungsrisiko senken, Erkrankte frueh*
54 *erkennen und behandeln*, Köln
55
56 Hader C et al (2004) *Diagnostik, Therapie und Verlaufskontrolle des Diabetes mellitus im*
57 *Alter*. In: Scherbaum WA, Kiess W (eds) *Evidenzbasierte Diabetes-Leitlinie der Deutschen*
58 *Diabetes-Gesellschaft (DDG) und der Deutschen Gesellschaft für Geriatrie (DGG)* (
59
60
61
62
63
64
65

1
2
3
4 [http://www.deutsche-diabetes-](http://www.deutsche-diabetes-gesellschaft.de/redaktion/mitteilungen/leitlinien/EBL_Alter_2004.pdf)
5 [gesellschaft.de/redaktion/mitteilungen/leitlinien/EBL_Alter_2004.pdf](http://www.deutsche-diabetes-gesellschaft.de/redaktion/mitteilungen/leitlinien/EBL_Alter_2004.pdf) [Access: 22.07.2008]
6

7 Hasseler M, Remmers H (2007) Pflegesprechstunden in der Primärversorgung - Prävention in
8 Diabetes mellitus Typ 2 durch integrierte, wohnortnahe und berufsgruppenübergreifende
9 Schulung, Anleitung und Beratung, (non-published manuscript)
10

11 Hirsch A (2002) Empowerment bei Diabetes: den eigenen Weg finden. In: Lange K, Hirsch A
12 (eds) Psycho-Diabetologie: personenzentriert beraten und behandeln. Kirchheim-Verlag,
13 Mainz, pp 10-27
14

15 Kerner W et al (2001) Definition, Klassifikation und Diagnostik des Diabetes mellitus. In:
16 Scherbaum WA, Lauterbach KW, Joost HG (eds) Evidenzbasierte Diabetes-Leitlinien
17 DDG (1st edn)
18 [http://www.deutschediabetesgesellschaft.de/redaktion/mitteilungen/leitlinien/EBL_Klassifi-](http://www.deutschediabetesgesellschaft.de/redaktion/mitteilungen/leitlinien/EBL_Klassifikation_Update_2004.pdf)
19 [kation_Update_2004.pdf](http://www.deutschediabetesgesellschaft.de/redaktion/mitteilungen/leitlinien/EBL_Klassifikation_Update_2004.pdf) [Access: 28.07.2008]
20
21
22

23 Kulzer B, Hermanns, N (1995) Verhaltensmedizinische Ansätze zur Gewichtsreduktion bei Typ
24 II Diabetikern. In: Petermann F (ed) Diabetes mellitus – Sozial- und
25 verhaltensmedizinische Ansätze. Hogrefe-Verlag für Psychologie, Göttingen, pp 141-185
26
27

28 Lamnek S (2005) Qualitative Sozialforschung. 4th edn, Beltz-Verlag, Weinheim, Basel
29

30 Lange K et al (2002) Ältere Menschen mit Diabetes: Stärken erkennen und nutzen. In: Lange K,
31 Hirsch A (eds) Psycho-Diabetologie: personenzentriert beraten und behandeln. Kirchheim-
32 Verlag, Mainz, pp 132-149
33

34 Liebl A. et al (2001) Kosten des Typ-2-Diabetes in Deutschland. Deutsche medizinische
35 Wochenzeitschrift, 126:585-589
36
37

38 Mayring P (1990) Einführung in die qualitative Sozialforschung: Eine Anleitung zum
39 qualitativen Denken, 1st edn. Psychologie-Verlags-Union, München
40

41 Mielck A, Helmert U (2006) Soziale Ungleichheit und Gesundheit. In: Hurrelmann K., Laaser
42 U., Razum O. (eds) Handbuch Gesundheitswissenschaften (4th edn), Juventa Verlag
43 Weinheim, München, pp 603-624
44

45 Möller J. et al (2004) Patientenschulung in der Hausarztpraxis als Beitrag zum Disease
46 Management. Qualitative Studie über Motive und Hindernisse bei der Durchführung von
47 Schulungen für Typ-2-Diabetiker. Zeitschrift für Allgemeinmedizin 80:146-149
48
49

50 NAFDM (2006) Nationales Aktionsforum Diabetes mellitus: Leitfaden Prävention Diabetes
51 mellitus Typ 2
52

53 Petermann F, Wendt A (1995) Verhaltensmedizinische Ansätze bei Diabetes mellitus – eine
54 Übersicht. In: Petermann F. (ed) Diabetes mellitus – Sozial- und verhaltensmedizinische
55 Ansätze. Hogrefe-Verlag für Psychologie, Göttingen, pp 67-108
56
57

58 Rosenbock R, Gerlinger T (2004) Gesundheitspolitik. Eine systematische Einführung. 1st edn,
59 Hans Huber Verlag, Bern, Göttingen, Toronto
60
61

- 1
2
3
4 Schneider M. et al (1999) Krankheitsbewältigung und Krankheitsbelastung älterer Menschen
5 mit Diabetes mellitus. In: Herpertz S, Paust R (eds) Psychosoziale Aspekte in Diagnostik
6 und Therapie des Diabetes mellitus. Pabst Science Publishers, Lengerich, Berlin,
7 Düsseldorf, Leipzig, Riga, Scottsdale (USA), Wien, Zagreb, pp 205-213
8
9
10 Schwarzer R (1996) Psychologie des Gesundheitsverhaltens, 2nd edn, Göttingen, Hogrefe
11
12 Seidl E et al (2007) Diabetes – Der Umgang mit einer chronischen Krankheit, Böhlau Verlag,
13 Wien, Köln, Weimar
14
15 Taylor KI et al (2005) Promoting Health in Type 2 Diabetes: Nurse-Physician Collaboration in
16 Primary Care. Biological Research For Nursing 6: 207-215
17
18 Vogt I (2006) Psychologische Grundlagen der Gesundheitswissenschaften. In: Hurrelmann K,
19 Laaser U, Razum O (eds) Handbuch Gesundheitswissenschaften, 4th edn, Juventa Verlag
20 Weinheim, München, pp. 147-182
21
22
23 Witzel A (2000) Das problemzentrierte Interview [26 Absätze]. Forum Qualitative
24 Sozialforschung / Forum: Qualitative Social Research [On-line Journal], 1,
25 <http://qualitative-research.net/fqs> [Access: 18.05.2008]
26
27
28 Wong FKY, Chung L (2006) Establishing a definition for a nurse-led clinic: structure, process,
29 and outcome, JAN 53:358-369
30
31 Woods-Büggeln S (2002): Psychologische Standards in der Diabetesschulung: die Patienten
32 verstehen. In: Lange K, Hirsch, A (eds) Psycho-Diabetologie: personenzentriert beraten
33 und behandeln. Kirchheim-Verlag, Mainz, pp 46-59
34
35
36
37
38
39
40
41
42
43
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