BMJ Open

Information needs of people with recently diagnosed diabetes mellitus: results from the German Diabetes Study.

Journal:	*BMJ Open*
Manuscript ID	bmjopen-2017-017895
Article Type:	Research
Date Submitted by the Author:	08-Jun-2017
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Primary Subject Heading:	Diabetes and endocrinology
Secondary Subject Heading:	Health services research, Patient-centred medicine
Keywords:	recently diagnosed diabetes mellitus, information needs, German Diabetes Study, patient-centred care

Information needs of people with recently diagnosed diabetes mellitus: results from the German Diabetes Study.

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Funding statement

The German Diabetes Study was initiated and is financed by the DDZ – German Diabetes Center, which is funded by the German Federal Ministry of Health (Berlin, Germany) and the Ministry of Innovation, Science, Research and Technology of the state North Rhine-Westphalia (Düsseldorf, Germany). The present analysis was funded by the German Federal Ministry of Education and Research (BMBF) within the German Center for Diabetes Research (DZD e.V.) and by the Research Commission of the Faculty of Medicine of the Heinrich Heine University Düsseldorf.

Disclosure

There is no conflict of interest.

Word count: 3.563, Abstract: 258, Number of figures: 2, Number of tables: 1

Abstract

Objectives

This study aimed to identify (i) information needs of people with recently diagnosed type 1 as well as type 2 diabetes mellitus (DM); (ii) information needs within different subgroups; and (iii) factors or concepts associated with information needs concerning DM such as level of current information, quality of life or participation preferences.

Design

Using a mixed-method approach, combining quantitative and qualitative methods, we described information needs for different topics and estimated associated factors using logistic regression models. Additionally, a qualitative content analysis was performed.

Setting

Multicenter study.

Participants

We assessed and analyzed information needs in 138 consecutive participants with DM of the German Diabetes Study (54 % type 2 diabetes, 64 % male, mean age 46.3 ± 12.3 years, known diabetes duration <1 year).

Results

Most participants showed an information need in all topics provided, especially in diabetes research (86 %) and treatment/therapy (80 %). In terms of these topics, participants wished for information regarding new treatments that simplify their everyday life. In general, participants preferred topics that focus on management or handling of DM over topics related to clinical factors of DM, such as causes and complications. A low level of current information and treatment with oral glucose-lowering drugs or with insulin were associated with higher information needs, and diabetes-related comorbidity with lower information needs ($p < 0.05$ for specific outcomes).

Conclusion

People with recently diagnosed DM present with high information needs, which differ with respect to the level of current information, mode of diabetes treatment and diabetes-related comorbidity. This should be considered in patient information activities.

Strengths and limitations of this study

• A strength of the study is the possibility to analyze information needs in patients with recently diagnosed diabetes, a relevant patient group for the provision of suitable information.

• We were able to analyze a large number of variables as possible risk factors and confounders for information needs.

• A limitation is the cross-sectional design.

• Further, this observational study was not designed as a population-based study with a representative sample; for example, our cohort included more male and younger as well as more highly educated participants.

Introduction

Diabetes mellitus (DM) is comprised of different abnormalities associated with chronic hyperglycemia, and is characterized by complex self-management tasks (1). High health literacy is necessary to manage day-to-day challenges effectively. Health literacy combines '(…) knowledge, motivation and competences to access, understand, appraise, and apply health information in order to make judgments and take decisions in everyday life (…)' relating to health (2). To identify relevant information, people with DM need to transform their information needs into information-seeking strategies (3). An information need is defined as the 'recognition that their knowledge is inadequate to satisfy a goal, within the context/situation that they find themselves at a specific point in the time' (4). Compared with other diseases, such as cardiovascular and respiratory diseases, people with DM show a higher information need (5). Emotional reactions affect health-related information needs because of long-term illness that threatens life, as present in DM (3). To enable medical decision making, patients required high-quality and evidence-based information (6). Despite existing efforts to improve available information, patients' information needs are frequently disregarded.

While physicians are still the most important source of information for patients with diabetes (7), younger people seek or retrieve information from the Internet. It seems that the prevalence of diabetes complications increases in some cases if information is not provided as needed, e.g. unconscious needs are not identified or information sources are missing (8).

Surprisingly, there is a lack of studies addressing the information needs of people with DM, in particular in people with recently diagnosed diabetes. As of today, there is only one study analyzing information needs in patients with recently diagnosed diabetes (9). However, only people with type 2 diabetes were involved, and only qualitative methods were used. Several questions remain without answers, such as whether there are differences between patient subgroups, and which factors are associated with information needs.

Thus, this study aims to identify and analyze (i) information needs of people with recently diagnosed type 1 as well as type 2 DM; (ii) information needs within different subgroups; and (iii) factors or concepts associated with information needs concerning DM such as level of current information, quality of life or participation preferences.

Methods

Study design and population

This cross-sectional study combined quantitative and qualitative methods (mixed methods) using baseline data of participants in the German Diabetes Study (GDS). GDS is an ongoing prospective multi-center observational study, which was initiated and is coordinated by the German Diabetes Center (10). This study aims to investigate the course of disease and the consequences of DM, and has been described in detail elsewhere (10). Briefly, participants are 18- to 69-year-old people with recently diagnosed DM with a duration of less than 12 months of known diabetes. Data assessment comprises standardized questionnaires and interviews, detailed physical examinations and comprehensive metabolic phenotyping.

The present analysis included 157 consecutive participants in GDS between February 2014 and May 2016. Nineteen participants were excluded due to missing variables, yielding 138 for the final analysis.

Assessment of information needs

Information needs were assessed using a questionnaire developed and evaluated by Chernyak *et al*. The German language version has been previously applied to a clinic-based population of people with DM (11). This questionnaire is based on a mixed-methods design (11), a partially mixed concurrent equal-status design, assessing both quantitative and qualitative data (12), without prioritizing either of the methods.

It includes 11 topics of information needs (11): 'causes of diabetes', 'course of the disease', 'treatment/therapy', 'acute complications', 'late complications', 'diabetes in everyday life', 'mental strain', 'lifestyle adjustment, health promotion and prevention', 'support, helplines and information sources', 'social and legal aspects' and 'diabetes research'. Patients were able to mark for each topic if information is currently needed (no=0 / yes=1), and prioritize a number of the main information needs topics. Furthermore, patients stated for each topic how well they regard their personal information level (very well, well, not well, not informed at all). Additionally, they could add an individual unlisted information need. A blank text field was provided per information need to specify selected needs: 'Please explain what particular interests you have about these topics'. At the end of the information needs questionnaire, the participants had the opportunity to reply to the question 'What do you consider to be particularly important with regard to information on diabetes?' in a blank text field.

Variables

Outcome information needs

Three categories of information were defined. The first was the wish for information (no=0 / yes=1) on diabetes research. The second category, clinical topics, included causes of diabetes, course of the disease, acute complications, long-term complications and mental strain, and focused topics related to clinical factors of DM. The third category, management-related topics, combined the topics treatment/therapy, diabetes in everyday life, lifestyle adjustment, health promotion and prevention, support, helplines and information sources, and social and legal aspects, and focused on management or handling of DM. Within the second and third categories, results were summed up and dichotomized to 'low information needs' (ranging from 0 to 2) as well as 'high information needs' (ranging from 3 to 5).

Associated factors of information needs

The information needs questionnaire included questions about level of current information. According to the coding of information needs, answers to the topics of categories two and three were summed up and dichotomized to 'high level of current information' (ranging from 0 to 6) as well as 'low level of current information' (ranging from 7 to 15).

The further associated factors were taken from the data assessed in GDS as described above. First, a set of variables was selected from the literature for quantitative analysis (13–18). Studies showed that age (years), sex, education, type of diabetes, mode of diabetes treatment and health status seem to have an impact on information needs (13–18). Education was coded by 'other graduation' and 'university degree'; the type of diabetes was coded by 'type 1', 'type 2' and 'other' (not included in regression analysis); mode of diabetes treatment was coded by 'no drugs', 'oral glucose-lowering drugs' and 'insulin'. Health status was operationalized by diabetes-related comorbidities (nephropathy, neuropathy, peripheral arterial occlusive disease, myocardial infarction, stroke, transient ischemic attack).

Second, a set of explorative variables was selected: employment coded by 'no' or 'yes'; school graduation operationalized by 'other graduation' and 'graduation from high school'; and migration background, operationalized by place of birth other than Germany or nationality other than German. Regarding DM, the duration (time at the beginning to survey time), HbA_{1c} and number of overall drugs were included.

Self-reported participation preferences, and thus the wish to be involved in medical decision making, were measured by the Control Preference Scale, coded by 'passive role', 'collaborative role' and 'active role' (19). Depression was measured with the instruments Center for Epidemiological Studies Depression Scale, long German version (ADS-L) (20) and Problem Areas in Diabetes (PAID) survey (21, 22). In relation to the respective published evaluation methods, we coded depression within ADS-L by 'clinically relevant depression' and within PAID by 'severe

diabetes-related distress'. Quality of life was measured with the 36-Item Short-Form Health Survey (SF-36) (23, 24), analyzed by the physical and mental summary scales. In addition, the 5-Item World Health Organization Well-Being Index (WHO-5) questionnaire was analyzed, and quality of life was coded by 'low quality of life' and 'high quality of life' (25).

Self-management was operationalized using three questions to be answered with yes or no: 'Do you have a health pass for diabetes?', 'Do you perform glucose self-monitoring?' and 'Have you ever participated in an education program for people with diabetes?'. We included variables that allow statements on the lifestyle of the participants: body-mass index (BMI), smoking behavior and leisure time activity. BMI was categorized as defined by the World Health Organization (2005) (26), smoking behavior was coded by 'no answer', 'no' and 'yes'. Leisure time activity was operationalized by the Baecke index (27, 28), as a summary of the variables: 'During leisure hours, I walk', 'During leisure hours, I ride a bike' and 'For how many minutes a day do you walk or ride a bike going back and forth from work, school or shopping?'.

Quantitative analysis

First, the descriptive analyses were performed (depending on the distribution of the variables by frequencies, percentages, means ± standard deviations). To estimate associations between the information need categories as described above and associated factors, multivariate logistic regression models were fitted. Three groups of models were fitted, using as dependent binary variable the need for information on diabetes research, clinical topics and management-related topics. Different models were fitted including different groups of independent variables: level of current information, age, sex, education, type of diabetes, mode of diabetes treatment, diabetes-related comorbidity, employment, school graduation, migration background, duration of diabetes, HbA_{1c}, number of overall drugs, participation preferences, depression, quality of life, self-management and lifestyle (BMI, smoking behavior, leisure time activity). Finally, variables were

selected with regard to medical and statistical aspects; three final models (one per outcome) of similar structure are presented summarizing the analyses. The odds ratios (ORs) were calculated with a 95 % confidence interval (CI). We used SAS version 9.4 for all analyses.

Qualitative analysis

The qualitative content analysis was used for the free text entries and performed according to Elo and Kyngäs (2007) (29). One coder analyzed all entries and the other one reviewed the codings. A coding tree was developed. According to the questionnaire, the theoretical and deductive pre-defined information need categories were analyzed first deductively, added by inductive analysis process of developing subcategories. We analyzed the data several times to concretize the codings of information needs. Performing the inductive analysis, we started with 'open coding, creating categories and abstraction'. In this phase, we reduced and described the material with formulate higher-order categories.

Results

Participant Characteristics

About 60 % of the participants were male (table 1). About half of them had a university degree, and three quarters were employed. One in ten had a migration background. More than 50 % had type 2 diabetes, and about one fifth were treated without drugs. Participants took an average of three different drugs. Diabetes-related comorbidity was present in every sixth person.

Level of current information

Most participants were not well informed or not informed at all about the category diabetes research (n=91) (figure 1). In terms of clinical topics, the majority of participants reported that they were

very well or well informed about causes of diabetes (n=94), long-term complications (n=92), course of the disease (n=88) and acute complications (n=81). Not well informed or not informed at all constituted the majority only for the topic mental strain (n=85). The majority of participants reported that they were very well or well informed about the following management-related topics: treatment/therapy (n=103), diabetes in everyday life (n=87), and lifestyle adjustment, health promotion and prevention (n=79). Not well informed or not informed at all constituted the majority for the topics support, helplines and information sources (n=76), and social and legal aspects (n=100). There were more participants with a high level of current information on clinical topics (n=62) than with a high level of current information on management-related topics (n=47) (McNemar's test p=0.007).

Quantitative results

Information needs

The majority of participants wished to gain information in all provided topics of the questionnaire (figure 2). Most of them (n=103) wished to have more information about the category diabetes research. With regards to clinical topics, the participants showed the highest need for information on course of the disease (n=80). The lowest need was mentioned for information on acute complications (n=73) and mental strain (n=69). Management-related topics, e.g. treatment/therapy (n=99) and lifestyle adjustment, and health promotion and prevention (n=95), were generally more desired than clinical topics. The lowest information need for management-related topics was presented in support, helplines and information sources (n=73). Four participants reported no information need.

The participants prioritized information about diabetes research (n=52) more than most topics allocated to the other two categories. A high information need was also reported for the clinical topics long-term complications (n=51) and causes of diabetes (n=40). The topics course of the

disease (n=21) and mental strain (n=13) were rarely prioritized, especially the topic acute complications (n=5). The highest priority was reported for information about treatment/therapy as a management-related topic. In the category management-related topics, high information needs were also reported for lifestyle adjustment, health promotion and prevention (n=51), and diabetes in everyday life (n=42). The topics support, helplines and information sources (n=17), and social and legal aspects (n=14) were rarely prioritized.

Associated factors and concepts

Multivariate logistic regression analyses were performed using information needs (high versus low) in diabetes research, clinical topics and management-related topics separately. After discussion of the results of models using different groups of covariables, the following fixed sets of independent variables including confounders were selected for the three main models: Level of current information (high versus low), age, sex, education, mode of diabetes treatment (insulin, oral glucose-lowering drugs), diabetes-related comorbidity (binary), quality of life (SF-36 physical and mental score) and BMI (>30 kg/m² versus ≤30 kg/m²). The models were fitted after excluding patients with missing values in one of the variables in the model (outcome diabetes research: n=105, clinical topics: n=99 and management-related topics: n=100).

The level of current information, mode of diabetes treatment and diabetes-related comorbidity, are significantly associated with information needs: Participants, who reported high levels of information in clinical and management-related topics, were more likely to show a low information need in clinical as well as in management-related topics (OR with 95 % CIs: 0.33 (0.13–0.84) and 0.31 (0.10–0.91)). Participants treated with oral glucose-lowering drugs or insulin were more likely to have information needs regarding diabetes research compared to those without drug treatment (8.22 (1.61–41.82) and 56.1 (2.67–1178.7)). Existing comorbidities were associated with low information needs regarding diabetes research (0.05 (0.01–0.34)). The other factors (age, sex,

education, type of diabetes, employment, school graduation, migration background, duration of diabetes, HbA_{1c}, number of overall drugs, participation preferences, depression, quality of life, self-management, BMI, smoking behavior and leisure time activity) were not significantly associated with information needs; however, low power should be considered in the interpretation of the non-significant results.

Qualitative results

Qualitative analysis showed that participants who wished to have information about topics in the category diabetes research mentioned as specific needs information about study participation and results, scientific progress especially for cure, treatment (e.g. artificial pancreas) and technical devices (e.g. blood glucose measurement).

Specific information needs that were stated for clinical topics, such as causes of diabetes, were: causes of latent autoimmune diabetes in adults and people with type 1 diabetes at higher age. Participants wanted to know more about course of disease, especially with regard to a description of the disease process and positive influences on the course of the disease. Wishes for information about acute complications were not explained in more detail. Concerning long-term complications, participants mentioned information regarding conditions under which these occur, and prevention and recognition of symptoms as specific needs. Mental strain information needs were reported as the impact on daily life, stress management and fear of hypoglycemia.

Participants who were interested in the topics in the category management-related topics and desire information about treatment/therapy mentioned as specific needs: information on existing and new treatment options (e.g. continuous glucose monitoring, insulin pump therapy) and information about a simplified therapy, especially with less measuring and fewer insulin syringes. Specific needs in diabetes in everyday life were: coping strategies in certain situations using tips for simplification (e.g. holidays, work), diabetes management (e.g. time management, calculating insulin or bread

units) and exchanges with people with DM. Information needs in lifestyle adjustment, health promotion and prevention included interest in information about sports and nutrition, tips and strategies for a better handling of diabetes, as well as possibilities for exchanging experiences (e.g. health insurance, weight-loss clinic). In support, helplines and information sources, participants wished for an overview of existing support offers and education programs. Participants who prioritized social and legal aspects wanted information about diabetes as a disability and job-related information (e.g. termination).

The results of the last open question showed that it is preferred when information is provided personally, in form of a brochure and videos, or in specific information events. Information should always be provided over time, especially recently after diagnosis and when new insights become known. Information should be comprehensive, transparent, neutral and of high quality. In addition, the participants expressed the wish that information be adapted to their level of knowledge.

Synthesis of quantitative and qualitative results

The topic with the highest interest was diabetes research, and with regard to the category management-related topics particularly the topic treatment/therapy. Concerning diabetes research, participants wanted more information on new treatments and technical devices. In both topics, there was a strong desire for information about new insights to simplify treatment. In particular, individual characteristics, such as existing knowledge, seem to be relevant regarding information needs and information provision. Simplification and disease management are qualitative core aspects that seem to be relevant in the context of coping strategies in daily live and regarding further information needs, as well as regarding information behavior as information sources and information provision.

Discussion

Participants with recently diagnosed DM have a high information need in all topics concerning diabetes that were assessed with the information needs questionnaire. They need information related to diabetes research and prefer more management-related topics than clinical topics. Information needs concerning DM seem to be associated with level of current information, mode of diabetes treatment, and diabetes-related comorbidity.

The highest information need addressed diabetes research. This may be due to the fact that our participants who participate in the GDS are more interested in research questions then people with DM who do not participate in a research study (10, 30). The interest in information on recent science progress has also been reported in another study (8).

In general, participants desired more information on management-related topics than on clinical topics. It can be assumed that this is related to the stage at which the recent diagnosis of diabetes was made and a presumably better health status. A high need for information about treatment/therapy has also been found in other studies (8, 9, 13, 17, 31–34).

The analysis of the two categories clinical topics and management-related topics showed that a low level of current information is associated with a higher need for information. However, information is required with regard to treatment/therapy, despite a high level of current information. In contrast, information on mental strain was rarely prioritized, although a low level of current information was reported. St. Jean (2016) reported a possible lack of information sources or unconscious information needs as reasons that relevant information cannot be obtained (8).

Pharmaceutical diabetes treatment seems to be associated with a higher need for information on diabetes research. This finding confirms a focus group analysis by Lamberts et al. (2010), which showed a higher information need for drug-related information in people who have recently started treatment with oral glucose-lowering drugs (17).

Surprisingly, diabetes-related comorbidity was associated with a lower information need in diabetes research. No other study reported this association. We adjusted for the current level of information, but we cannot exclude that people with diabetes-related comorbidities are already well informed.

We found no associations between information needs and sex, age, sociodemographic or further variables, possibly due to an insufficient power to detect further significant associations.

Limitations and strengths

This observational study was not designed as a population-based study and therefore does not claim to represent the total German diabetes population, but intends to reveal predictors associated with later outcomes in specific subgroups and to unravel underlying mechanisms (35). Compared with population-based representative samples, our cohort included more male and younger as well as more highly educated participants. Nevertheless, anthropometric data, such as BMI, were comparable to other German or European cohorts (35). Furthermore, bias introduced by referral of possibly more motivated patients needs to be considered. Of note, one might suggest a higher level of information in such patients.

A limitation of the study is its relatively low sample size and a large number of variables to be investigated as possible risk factors and confounders for information need. There is low power to detect weaker associations. The results should therefore be interpreted with caution. In the 'final models', associations might be overweighted because of data-driven selection. Due to the low sample size it was not possible to separate the data into two sets of training and test data for model building and validating the final model. Furthermore, no adjustment for multiple testing was performed.

The strengths of the study are the possibility to analyze information needs in patients with recently diagnosed diabetes, a relevant patient group for the provision of suitable information. Of note,

information needs may rise with the progression of the disease (8). The longitudinal design of GDS will allow a prospective analysis of the patients in this study.

Conclusion

In people with recently diagnosed diabetes, there is currently a high information need for all topics concerning diabetes, especially diabetes research and management-related topics. Information needs differ between patient groups in that information needs are associated with the level of current information, mode of diabetes treatment and diabetes-related comorbidity. This has to be considered when patients are provided with information about their disease. An open question is how information needs might change during the course of disease. The prospective GDS provides the opportunity to analyze this question in the future.

Author's contribution

AI, MR, JS, KM, VB, SG, SK, NE, AS, JG and GDS Group contributed to the concept, design, and drafting of the pilot study. AI, SG, SK, AB, BH developed the design of the analysis. SG, AB, BH conducted formal analysis. SK and AI supervised the process of analysis. SG, SK and AI made contributions to the write-up the manuscript and all authors to edit it. All authors read and approved the final manuscript.

Data Sharing Statement

All available data can be obtained from the corresponding author.

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Table 1. Participants' characteristics

characteristics		N (%)	mean (SD)
total number of participants		138	
age, n=138			46.3 (12.3)
sex, n=138	male	88 (64)	
	female	50 (36)	
university degree, n=135		64 (47)	
employment, n=137		111(81)	
migration background, n=136		18 (13)	
type of diabetes, n=138	type 1	56 (41)	
	type 2	75 (54)	
	other	7 (5)	
mode of diabetes treatment, n=130	no drugs	26 (20)	
	oral glucose-lowering drugs	51 (39)	
	insulin	50 (38)	
	oral glucose-lowering drugs and insulin	3 (2)	
number of overall drugs, n=130			2.98 (1.91)
diabetes-related comorbidity, n=136		23 (17)	

Figure 1. Level of current information of the study population on the diabetes-related topics (2–6 missings per variable)

Figure 2. Information needs of the study population (15–22 missings per variable)

Figure 1

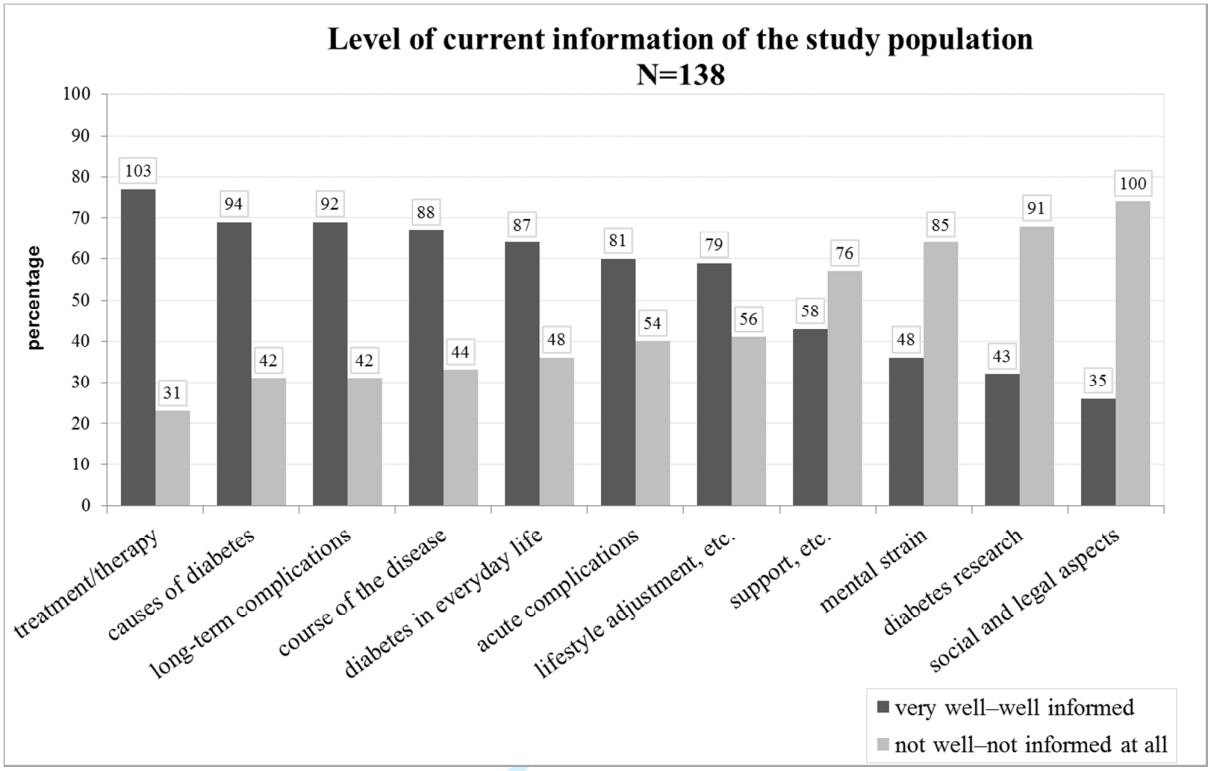
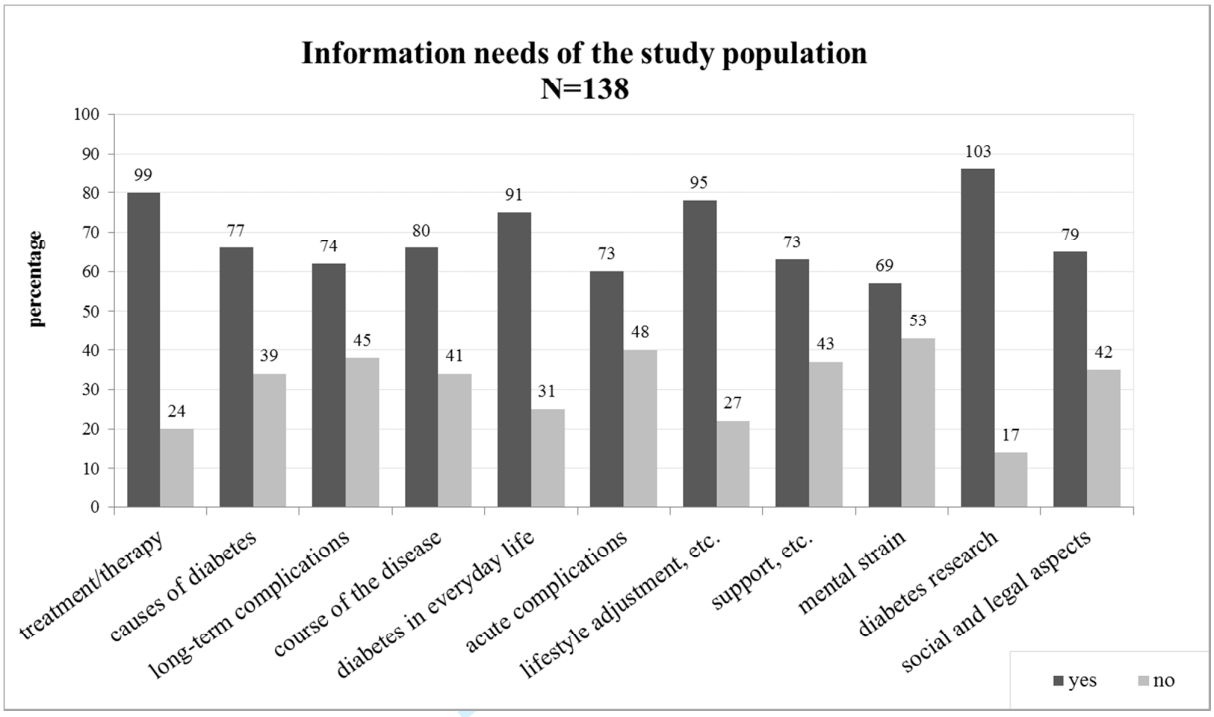


Figure 2



BMJ Open

What information needs do people with recently diagnosed diabetes mellitus have and what are the associated factors? A cross-sectional study in Germany

Journal:	*BMJ Open*
Manuscript ID	bmjopen-2017-017895.R1
Article Type:	Research
Date Submitted by the Author:	15-Apr-2018

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Primary Subject Heading:	Diabetes and endocrinology
Secondary Subject Heading:	Health services research, Patient-centred medicine
Keywords:	recently diagnosed diabetes mellitus, information needs, German Diabetes Study, patient-centred care

What information needs do people with recently diagnosed diabetes mellitus have and what are the associated factors? A cross-sectional study in Germany

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Funding statement

The present study was funded by the German Federal Ministry of Education and Research (BMBF) to the German Center for Diabetes Research (DZD e.V.), and the Research Commission of the Faculty of Medicine of the Heinrich Heine University Düsseldorf. The German Diabetes Study was initiated and financed by the DDZ – German Diabetes Center, which is funded by the German Federal Ministry of Health (Berlin, Germany) and the Ministry of Culture and Science of the state North Rhine-Westphalia (Düsseldorf, Germany) and from the German Federal Ministry of Education and Research (BMBF) to the German Center for Diabetes Research (DZD e.V.).

Disclosure

There are no conflicts of interest.

Word count: 4.277, Abstract: 292, Number of figures: 2, Number of tables: 1

Abstract

Objectives

This study aimed to identify (i) information needs of people with recently diagnosed type 1 or type 2 diabetes mellitus (DM); (ii) information needs within different subgroups; and (iii) factors or concepts associated with information needs concerning DM such as current level of information, health-related quality of life or participation preferences.

Design

Using a mixed-method approach combining quantitative and qualitative methods, information needs for different topics and estimated associated factors were described using logistic regression models. Additionally, a qualitative content analysis was performed.

Setting

Monocentre study.

Participants

Information needs were assessed and analysed in 138 consecutive participants with DM who took part in the German Diabetes Study (54 % type 2 diabetes, 64 % male, mean age 46.3 ± 12.3 years, known diabetes duration <1 year).

Results

Most participants displayed a need for information in all topics provided, especially in diabetes research (86 %) and treatment/therapy (80 %). Regarding those topics, participants wished for information regarding new treatments that simplify their everyday life. In general, participants preferred topics that focus on the management or handling of DM over topics related to clinical factors of DM, such as causes and complications. A low current level of information and treatment with antihyperglycemic medication were significantly associated with higher information needs, and diabetes-related comorbidity and higher mental component summary score of the SF-36 with lower information needs.

Conclusion

People with recently diagnosed DM display high information needs, which differ according to the current level of information, mode of diabetes treatment, diabetes-related comorbidity and mental component summary score of the SF-36. There appears to be a preference for information, which can help to simplify life with diabetes and for information which corresponds to their level of knowledge. This should be considered in patient information activities.

Strengths and limitations of this study

- A strength of the present study is the ability to analyse information needs in people with recently diagnosed diabetes, a relevant patient group for the provision of suitable information.
- A large number of variables and their association with information needs could be analysed.
- A limitation is the cross-sectional design.
- Furthermore, the present observational study was not designed as a population-based study with a representative sample; for example, our cohort included more male and younger participants as well as more highly educated participants.

Introduction

Diabetes mellitus (DM) is composed of different abnormalities associated with chronic hyperglycaemia, and is characterized by complex self-management tasks (1). Patients require high-quality and evidence-based information to enable adequate decision-making (2). People with DM show a higher information need compared to people with other diseases, such as cardiovascular and respiratory diseases (3). However, despite existing efforts to improve available information and a growing discussion of associated concepts such as health literacy, patients' information needs are frequently disregarded.

A recent systematic review revealed surprisingly few studies addressing the information needs of people with DM (4), in particular in people with recently diagnosed diabetes. As of today, there is only one study which analyses information needs in people with recently diagnosed diabetes (5). However, only people with type 2 diabetes were involved, and only qualitative methods were used. Several questions remain unanswered, such as whether there are differences between patient subgroups and which factors are associated with information needs.

Thus, the present study aims to identify and analyse (i) information needs of people with recently diagnosed type 1 or type 2 DM; (ii) information needs within different subgroups; and (iii) factors or concepts associated with information needs concerning DM such as current level of information, health-related quality of life or participation preferences. An information need is defined as the 'recognition that their knowledge is inadequate to satisfy a goal, within the context/situation that they find themselves at a specific point in the time' (6).

Methods

Study design and population

The present cross-sectional study combined quantitative and qualitative methods (mixed-methods) using baseline data of participants in the German Diabetes Study (GDS). GDS is an ongoing

prospective observational study initiated and coordinated by the German Diabetes Center (7). The GDS aims to investigate the course of disease and the consequences of DM, and has been described in detail elsewhere (7). Participants are people aged between 18 and 69 with recently diagnosed DM with a duration of less than 12 months of known diabetes. Data assessment comprises standardised questionnaires and interviews, detailed physical examinations and comprehensive metabolic phenotyping.

The present study included 157 consecutive participants from the GDS between February 2014 and May 2016. Nineteen participants were excluded due to missing variables, yielding 138 for the final analysis.

Ethical approval

The GDS was approved by the ethics committee of Heinrich Heine University Düsseldorf (study reference number 4508, previous reference number 2478). This study is performed according to the Declaration of Helsinki and registered at Clinicaltrials.gov (Identifier: NCT01055093) (7).

Patient and Public Involvement

Patients and public were not involved in the present study. The questionnaire for measuring the need for information was developed with the participation of people with DM in focus groups.

Assessment of information needs

Information needs were assessed using a questionnaire developed and evaluated by Chernyak *et al.* (8). The German language version has been previously applied to a clinic-based population of people with DM (8). The questionnaire is based on a mixed-methods design, namely a partially mixed concurrent equal-status design (9). Both quantitative and qualitative data were assessed without prioritising either of the methods.

It includes 11 topics of information needs (8): 'causes of diabetes', 'course of the disease', 'treatment/therapy', 'acute complications', 'late complications', 'diabetes in everyday life', 'mental strain', 'lifestyle adjustment, health promotion and prevention', 'support, helplines and information sources', 'social and legal aspects' and 'diabetes research'. Patients are able to mark whether information is currently needed (no=0 / yes=1) for each topic and prioritise a number of the main information needs. Furthermore, patients assess their current level of information for each topic (very well, well, not well, not informed at all). Additionally, they can add an individual unlisted information need. A blank text field is provided per information need to specify selected needs: 'Please explain what particular interests you have about these topics'. At the end of the information needs questionnaire, the participants have the opportunity to reply to the question 'What do you consider to be particularly important with regard to information on diabetes?' in a blank text field.

Variables

Outcome: category of information need

Three categories of information needs were defined for the purposes of the present study. The first was the desire for information (no=0 / yes=1) on diabetes research. The second category focussed on topics related to clinical factors of DM including a need for information on the causes of diabetes, course of the disease, acute complications, long-term complications and mental strain. The needs identified in the third category focussed on the management and handling of DM including management-related topics, treatment/therapy, diabetes in everyday life, lifestyle adjustment, health promotion and prevention, support, helplines and information sources, and social and legal aspects. Within the second and third categories, results were summed up and dichotomised into 'low information needs' (ranging from 0 to 2) or 'high information needs' (ranging from 3 to 5).

Factors associated with information needs

The associated factors were taken from the data assessed in GDS as described above. The variables were selected as follows: firstly, a set of variables was deduced empirically from the existing literature for quantitative analysis (10–15). Studies showed that age (years), sex, education, type of diabetes, mode of diabetes treatment and health status appear to have an impact on information needs (10–15). Education was coded by 'other graduation' and 'university degree'; the type of diabetes was coded by 'type 1', 'type 2' and 'other'; mode of diabetes treatment was coded by 'no antihyperglycemic medication', 'oral glucose-lowering drugs' and 'insulin'. Health status was defined according to diabetes-related comorbidities (nephropathy, neuropathy, peripheral arterial occlusive disease, myocardial infarction, stroke, transient ischemic attack).

Secondly, five explorative groups of thematically relevant variables in the context of diabetes were developed on a theoretical basis: (i) socio-economic factors are associated with diabetes-related information-seeking behaviour (16). Further socio-economic factors in addition to education, which has already been included, were therefore included: employment coded by 'no' or 'yes'; school graduation defined as 'other graduation' and 'graduation from high school'; and migration background, denoted by place of birth other than Germany or nationality other than German.

(ii) Past diabetes experience is associated with information needs (4). It can therefore be assumed that diabetes-related and health-related factors may have an impact on information needs. Hence, besides diabetes type and mode of diabetes treatment which have already been included, the duration of DM (time since diagnosis until inclusion in the GDS), HbA_{1c} and number of overall drugs were also included.

(iii) As some studies on information needs also report on participation preferences and on the people's knowledge (4), this variable was added. Self-reported participation preferences, and thus the wish to be involved in medical decision-making, were measured by the Control Preference Scale, coded by 'passive role', 'collaborative role' and 'active role' (17). The information needs questionnaire included questions about current level of information. The current level of

information on diabetes research was coded by 'high current level of information' (very well or well informed) and 'low current level of information' (not well or not informed at all). The other two categories of information needs were summed up and dichotomised into 'high current level of information' (ranging from 0 to 6) as well as 'low current level of information' (ranging from 7 to 15).

(iv) The fourth group of variables refers to depression and health-related quality of life. People with DM have a higher prevalence of depression and a lower health-related quality of life than people without DM (18, 19). This may lead to a lower level of activity. Depression was measured using the Center for Epidemiological Studies Depression Scale, long German version (ADS-L) (20) and Problem Areas in Diabetes (PAID) survey (21, 22). In accordance with the respective published evaluation methods, depression was coded according to ADS-L as 'clinically relevant depression' (cut-off score >22) and according to PAID as 'severe diabetes-related distress' (cut-off score ≥40). Health-related quality of life was measured using the 36-Item Short-Form Health Survey (SF-36) (23, 24) and analysed according to the physical and mental summary scales. In addition, the 5-Item World Health Organization Well-Being Index (WHO-5) questionnaire was analysed and quality of life was coded as 'low quality of life' (ranging from 0 to 12) and 'high quality of life' (ranging from 13 to 25) (25).

(v) Several studies have found that 'self-management' and 'lifestyle' are the main contents of the information needs of people with DM (4), and thus the present study sought to identify a possible association. Self-management was operationalised using three questions to be answered with yes or no: 'Do you have a health pass for diabetes?', 'Do you perform glucose self-monitoring?' and 'Have you ever participated in an education programme for people with diabetes?'. Variables that provide statements on the participants' lifestyles were included: body-mass index (BMI), smoking behaviour and leisure time activity. BMI was categorised in accordance with the World Health Organization definition (2005) (26), smoking behaviour was coded by 'no answer', 'no' and 'yes'.

Leisure time activity was operationalised according to the Baecke index (27, 28) as a summary of the variables: 'During leisure hours, I walk', 'During leisure hours, I ride a bike' and 'For how many minutes a day do you walk or ride a bike going back and forth from work, school or shopping?'.

Quantitative analysis

Firstly, descriptive analyses were performed (depending on the distribution of the variables by frequencies, percentages, means ± standard deviations).

To estimate associations between the information need categories as described above and associated factors, multivariate logistic regression models were fitted, resulting in odds ratios (ORs) with 95% confidence intervals (CI). Three groups of models were fitted, using the need for information (high versus low) on diabetes research, clinical topics and management-related topics as a dependent binary variable.

The following steps were performed to select the final set of independent variables: We first included the six groups of variables described above fitting different models separately. We excluded variables due to many missing values, low impact in the regression analysis, low variation or high correlation to other covariables. Larger models were then fitted which included the independent variables of all six groups. After discussion of these models, fixed sets of independent variables including confounders were selected for the three main models. The final set of variables included: age, sex, education, type of diabetes (type 1 versus type 2), mode of diabetes treatment (antihyperglycemic medication yes versus no), diabetes-related comorbidity (binary), current level of information (high versus low), health-related quality of life (SF-36 physical and mental score) and BMI (>30 kg/m² versus ≤30 kg/m²).

With regard to the research-related information needs outcome, the corresponding model was only fitted in the subpopulation of subjects with type 2 diabetes, since all participants from the type 1

subgroup were in need of information on diabetes research. The models for the clinical and management-related information needs outcomes were run both for the whole study population as well as stratified for type 1 and type 2 diabetes. The mode of diabetes treatment was excluded for type 1 diabetes because only one participant in that subgroup did not use antihyperglycemic medication. SAS version 9.4 was used for all analyses.

Qualitative analysis

The qualitative content analysis was used for the free text entries and performed according to Elo and Kyngäs (2007) (29). A coding tree was developed by two coders, and one coder analysed all entries and the other reviewed the coding. According to the questionnaire, the theoretical and deductive pre-defined information need categories were first analysed deductively. A subsequent inductive analysis was performed to determine the subcategories. The inductive analysis entailed 'open coding, creating categories and abstraction'. During that phase, the data was abstracted and described in order to define higher-order categories. The data was analysed several times to substantiate the codings of information needs.

Results

Participant characteristics

Approximately 60 % of the participants were male (Table 1). About half of them had a university degree, and three quarters were employed. One in ten had a migration background. More than 50 % had type 2 diabetes, and about one fifth were treated without antihyperglycemic medication. Participants took an average of three different drugs. Diabetes-related comorbidity was present in every sixth person.

Most participants were not well informed or not informed at all about diabetes research (n=91) (Figure 1). Regarding clinical topics, the majority of participants reported that they were very well or well informed about causes of diabetes (n=94), long-term complications (n=92), course of the disease (n=88) and acute complications (n=81). Mental strain (n=85) was the only topic where not well informed or not informed at all constituted the majority. The majority of participants reported that they were very well or well informed about the following management-related topics: treatment/therapy (n=103), diabetes in everyday life (n=87), and lifestyle adjustment, health promotion and prevention (n=79). The majority of participants stated that they were not well informed or not informed at all regarding the topics support, helplines and information sources (n=76), and social and legal aspects (n=100). There were more participants with a high current level of information on clinical topics (n=62) than with a high current level of information on management-related topics (n=47) (McNemar's test p=0.007).

Quantitative results

Information needs

The majority of participants wished to gain information on all topics listed in the questionnaire (Figure 2). Most of them (n=103) wished to have more information about diabetes research. Of the clinical topics, participants showed the greatest need for information on the course of the disease (n=80). The lowest need was stated for information on acute complications (n=73) and mental strain (n=69). Management-related topics, e.g. treatment/therapy (n=99) and lifestyle adjustment, and health promotion and prevention (n=95) were generally of more interest than clinical topics. The lowest information need for management-related topics was found for support, helplines and information sources (n=73). Four participants stated no information need.

The participants prioritised information about diabetes research (n=52) more than most topics allocated to the other two categories. A high information need was also reported for the clinical

topics long-term complications (n=51) and causes of diabetes (n=40). The topics course of the disease (n=21) and mental strain (n=13), and especially the topic acute complications (n=5), were rarely prioritised. The highest priority was reported for information about treatment/therapy as a management-related topic. In the category management-related topics, high information needs were also reported for lifestyle adjustment, health promotion and prevention (n=51), and diabetes in everyday life (n=42). The topics support, helplines and information sources (n=17), and social and legal aspects (n=14) were rarely prioritised.

Associated factors and concepts

After excluding participants with missing values, the models were based on n=56 (diabetes research, only type 2), n=93 (clinical topics) and n=93 (management-related topics) participants.

The current level of information, mode of diabetes treatment, diabetes-related comorbidity and mental component summary score of the SF-36 are significantly associated with information needs: participants who reported high current levels of information in clinical and management-related topics were more likely to show a low information need both in clinical and management-related topics (OR with 95 % CIs: 0.33 (0.13–0.86) and 0.28 (0.09–0.89)). The other factors were not significantly associated with information needs; however, low statistical power should be considered in the interpretation of the non-significant results.

Subgroup analyses for patients with type 1 and type 2 diabetes showed that the current level of information in clinical and management-related topics is significantly associated with information need only in the type 1 diabetes (0.17 (0.03–0.92) and 0.11 (0.02–0.75)) group. In people with type 1 diabetes, higher mental component summary score of the SF-36 is associated with low information needs concerning management-related topics (0.87 (0.76–0.995)). Participants with type 2 diabetes treated with antihyperglycemic medication were more likely to have information needs regarding diabetes research compared to those without antihyperglycemic medication (6.98

(1.38–35.22)). Existing comorbidities in people with type 2 diabetes were associated with low information needs regarding diabetes research (0.04 (0.01–0.38)).

Qualitative results

Qualitative analysis showed that participants who sought information about topics in the category diabetes research specifically expressed a need for information on study participation and results, scientific developments (especially for cures, treatment (e.g. artificial pancreas)), and technical devices (e.g. blood glucose measurement).

Specific information needs that were stated for clinical topics, such as causes of diabetes, were: causes of latent autoimmune diabetes in adults and people with type 1 diabetes in older age. Participants wanted to know more about the course of the disease, especially a description of the disease process and positive influences on the course of the disease. Wishes for information about acute complications were not explained in more detail. As far as long-term complications are concerned, participants expressed specific needs for information regarding the conditions under which these long-term complications occur, and how symptoms can be prevented and recognised. Needs for information regarding mental strain included information on the impact on daily life, stress management and fear of hypoglycaemia.

Participants who were interested in the management-related topics category expressed specific information needs about treatment/therapy, in particular information on existing and new treatment options (e.g. continuous glucose monitoring, insulin pump therapy) and information about simplified therapy, especially with less measuring and fewer insulin syringes. Specific needs in diabetes in everyday life were: coping strategies in certain situations including tips for simplification (e.g. holidays, work), diabetes management (e.g. time management, calculating insulin or bread units) and interaction with people with DM. Information needs in the lifestyle adjustment, health promotion and prevention category included information about sports and

nutrition, tips and strategies for handling diabetes better, and possibilities to share experiences (e.g. health insurance, weight-loss clinic). In the support, helplines and information sources category, participants expressed interest in an overview of existing support offers and education programs. Participants who prioritised social and legal aspects wanted information about diabetes as a disability and job-related information (e.g. terminating employment).

The results of the last open question identified a preference for information to be provided personally, in brochure and video form, or at specific information events. Patients expressed a preference for information to be provided at all times especially recently after diagnosis and when new insights are gained, and for it to be comprehensive, transparent, neutral and of high quality. Furthermore, participants expressed a wish for information to be adapted to their level of knowledge.

Synthesis of quantitative and qualitative results

The greatest level of interest was shown in the two categories diabetes research and management-related topics, particularly the topic treatment/therapy in the latter. Where diabetes research is concerned, participants requested more information on new treatments and technical devices. In both topics, there was a strong desire for information about new insights to simplify treatment. Simplification and disease management are core qualitative aspects that appear to be relevant to coping strategies in daily live. Individual characteristics such as existing knowledge appear to be particularly relevant to information needs and information provision. It can also be noted that participants requested information to be adapted to their level of knowledge.

Discussion

Participants with recently diagnosed DM have a high information need in all the topics concerning diabetes that were assessed with the information needs questionnaire. They express a particular need for diabetes research and prefer more management-related topics than clinical topics. Information needs concerning DM seem to be associated with current level of information, mode of diabetes treatment, diabetes-related comorbidity, and mental component summary score of the SF-36.

The highest information need concerned diabetes research. This may be due to the fact that participants in the GDS are more interested in research questions than people with DM who do not participate in a research study (7, 30). The qualitative results indicate that participants wish information to be up-to-date with the latest scientific findings. Another aim could be to verify information provided by their physician (31). Other studies have also identified an interest in information on recent scientific development (4).

In general, participants requested more information on management-related topics than on clinical topics. The qualitative data clearly shows that the explanation of clinical topics frequently includes management-related information. For example, participants stated that they would like to receive more information on stress management. Resource-oriented provision of information is therefore more likely to meet the needs of people with recently diagnosed diabetes. It can be assumed that this is related to the stage at which the recent diagnosis of diabetes was made and a presumably better health status. A high need for information about treatment/therapy has also been identified by other studies (5, 12, 14, 31–34).

The analysis of the two categories clinical topics and management-related topics showed that a low current level of information is associated with a higher need for information. However, despite being currently well informed, participants still required information on treatment/therapy. An explanation could be: although people feel well informed, they do not have the specific information which helps them to achieve their personal goal (for instance the simplification of everyday life).

The qualitative data shows that a number of participants would like more detailed information that is adapted to their level of knowledge. In contrast, information on mental strain was rarely prioritised, although a low current level of information was reported. St. Jean (2016) posited that a lack of information sources or unconscious information could account for why relevant information cannot be obtained (31). The low information need concerning mental strain may also be explained by the fact that the recently diagnosed participants do not experience mental strain.

In people with type 2 diabetes, antihyperglycemic medication appears to be associated with a greater need for information on diabetes research. This finding confirms a focus group analysis by Lamberts et al. (2010), which showed a greater need for drug-related information in people who have recently started treatment with oral glucose-lowering drugs (14).

Surprisingly, diabetes-related comorbidity in people with type 2 diabetes was associated with a lower need for information for diabetes research. No other study reported this association. Adjustments were made for the current level of information, but it cannot be ruled out that people with diabetes-related comorbidities are already well informed.

In people with type 1 diabetes, higher mental component summary score of the SF-36 was associated with lower information needs in management-related topics. The health-related quality of life of people with type 1 diabetes is often reduced because of diabetes-related factors, for example fear of hypoglycaemia (also reported as an information need in the qualitative results) (35). In this study, people with higher mental component summary score of the SF-36 may feel that they do not need any further information to manage their situation. Other studies show that optimistic feelings and support in diabetes experience were associated with different information needs in people with DM (4). No associations were found between information needs and sex, age, type of diabetes or further variables, possibly due to an insufficient statistical power to detect further significant associations.

Regarding the clinical implications of this study, results may contribute to an adjustment of the design of communication strategies and education programmes at an early stage of the disease. Some people with DM felt that they received enough information about diabetes and therefore did not attend self-management education programmes (36). An individual and patient-centred approach to building programs can increase participation.

Limitations and strengths

The present observational study was not designed as a population-based study and therefore does not claim to represent the entire German diabetes population. Rather, it seeks to reveal predictors associated with later outcomes (e.g. diabetes-associated cardiovascular complications) in specific subgroups and to unravel underlying mechanisms (37). Compared with population-based representative samples, our cohort included more male and younger participants as well as more highly educated participants. Nevertheless, anthropometric data, such as BMI, was comparable to other German or European cohorts (37). However, the selection may introduce bias because the patients who participated in the GDS were potentially more motivated, which could suggest a higher current level of information.

A limitation of the present study is its relatively low sample size and the large number of variables to be investigated as possible risk factors and confounders for information need. There is low statistical power to detect weaker associations. The results should therefore be interpreted with caution. In the 'final models', associations might be overweighted because of data-driven selection. Due to the low sample size, it was not possible to separate the data into two sets of training and test data for model building and validation of the final model. Furthermore, no adjustment for multiple testing was performed.

The strengths of the present study are the possibility to analyse information needs in people with recently diagnosed diabetes, a relevant patient group for the provision of suitable information. It is

noted that information needs may rise with the progression of the disease (31). The longitudinal design of GDS will allow a prospective analysis of the patients in this study. Another strength is: a large number of variables and their association with information needs could be analysed.

Conclusion

In people with recently diagnosed diabetes, there is currently a high information need for all topics concerning diabetes, especially diabetes research and management-related topics, although study participants reported a relatively high level of being informed. Participants expressed a particular need for information regarding simplification of life with diabetes and for information adapted to their level of knowledge. Information needs differ between patient groups in that information needs are associated with the current level of information, mode of diabetes treatment, diabetes-related comorbidity and mental component summary score of the SF-36. This has to be considered when patients are provided with information about their disease. An open question is how information needs might change over the course of the disease. The prospective GDS provides the opportunity to analyse this question in the future.

Author's contribution

AI, MR, JS, KM, VB, SG, SK, UL, NE, AS, JG and GDS Group contributed to the concept, design, and drafting of the present study. AI, SG, SK, AB, BH developed the design of the analysis. SG, AB, BH conducted formal analysis. SK and AI supervised the analysis process. SG, SK and AI contributed to the writing of the manuscript; all authors were involved in editing. All authors read and approved the final manuscript. The GDS Group and their co-workers are responsible for the design and conduct of the GDS.

Data sharing statement

All available data can be obtained from the corresponding author.

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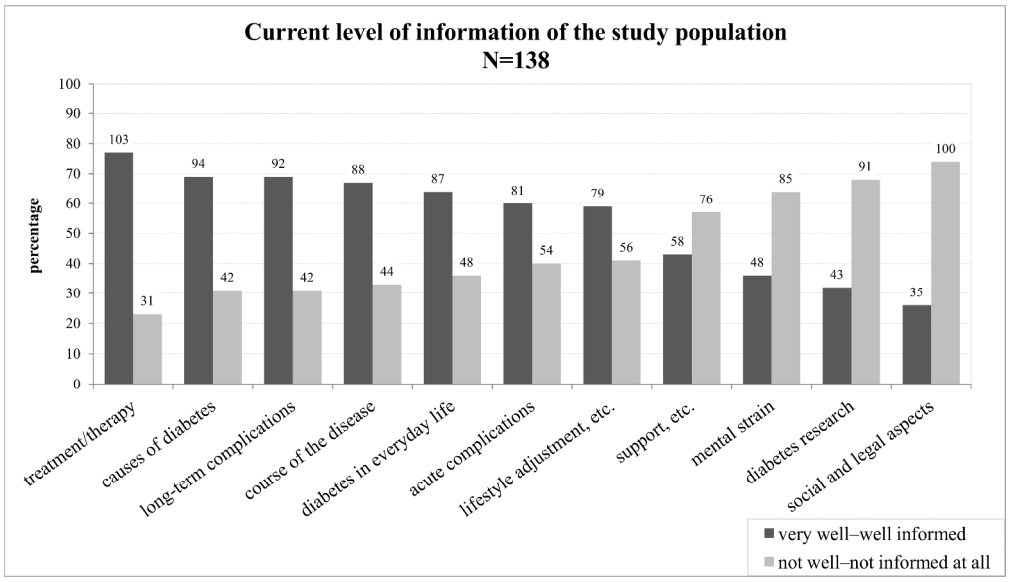
Table 1. Participants' characteristics

Characteristics		N (%)	mean (SD)
total number of participants		138	
age, n=138			46.3 (12.3)
sex, n=138	male	88 (64)	
	female	50 (36)	
university degree, n=135		64 (47)	
employment, n=137		111(81)	
migration background, n=136		18 (13)	
type of diabetes, n=138	type 1	56 (41)	
	type 2	75 (54)	
	other	7 (5)	
mode of diabetes treatment, n=130	no antihyperglycemic medication	26 (20)	
	oral glucose-lowering drugs	51 (39)	
	insulin	50 (38)	
	oral glucose-lowering drugs and insulin	3 (2)	
number of overall drugs, n=130			2.98 (1.91)
diabetes-related comorbidity, n=136		23 (17)	

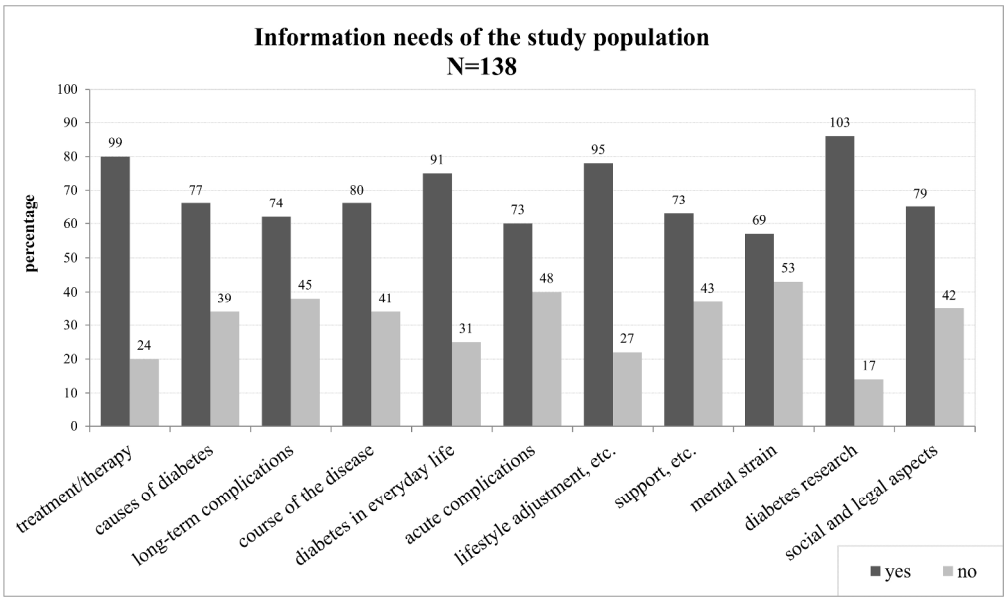
Figure 1. Current level of information of the study population on the diabetes-related topics (2–6 missings per variable)

Figure 2. Information needs of the study population (15–22 missings per variable)



Current level of information of the study population on the diabetes-related topics (2–6 missings per variable)

296x169mm (300 x 300 DPI)



Information needs of the study population (15–22 missings per variable)

296x175mm (300 x 300 DPI)

BMJ Open

What information needs do people with recently diagnosed diabetes mellitus have and what are the associated factors? A cross-sectional study in Germany

Journal:	*BMJ Open*
Manuscript ID	bmjopen-2017-017895.R2
Article Type:	Research
Date Submitted by the Author:	27-Jul-2018

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Primary Subject Heading:	Diabetes and endocrinology
Secondary Subject Heading:	Health services research, Patient-centred medicine
Keywords:	recently diagnosed diabetes mellitus, information needs, German Diabetes Study, patient-centred care

What information needs do people with recently diagnosed diabetes mellitus have and what are the associated factors? A cross-sectional study in Germany

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Funding statement

The present study was funded by the German Federal Ministry of Education and Research (BMBF) to the German Center for Diabetes Research (DZD e.V.), and the Research Commission of the Faculty of Medicine of the Heinrich Heine University Düsseldorf. The German Diabetes Study was initiated and financed by the DDZ – German Diabetes Center, which is funded by the German Federal Ministry of Health (Berlin, Germany) and the Ministry of Culture and Science of the state North Rhine-Westphalia (Düsseldorf, Germany) and from the German Federal Ministry of Education and Research (BMBF) to the German Center for Diabetes Research (DZD e.V.).

Disclosure

There are no conflicts of interest.

Word count: 4,335, Abstract: 291, Number of figures: 3, Number of tables: 1

Abstract

Objectives

This study aimed to identify (i) information needs of people with recently diagnosed type 1 or type 2 diabetes mellitus (DM); (ii) information needs within different subgroups; and (iii) factors associated with information needs concerning DM such as current level of information, health-related quality of life or participation preferences.

Design

A mixed-method approach combining quantitative and qualitative methods was used. Information needs for different topics and estimated associated factors were described using logistic regression models. Additionally, a qualitative content analysis was performed.

Setting

Monocentre study.

Participants

Information needs were assessed and analysed in 138 consecutive participants with DM who took part in the German Diabetes Study (54 % type 2 diabetes, 64 % male, mean age 46.3 ± 12.3 years, known diabetes duration <1 year).

Results

Most participants displayed a need for information in all topics provided, especially in diabetes research (86 %) and treatment/therapy (80 %). Regarding those topics, participants wished for information regarding new treatments that simplify their everyday life. In general, participants preferred topics that focus on the management or handling of DM over topics related to clinical factors of DM, such as causes and complications. A low current level of information and treatment with antihyperglycaemic medication were significantly associated with higher information needs, and diabetes-related comorbidity and higher mental component summary score in the SF-36 with lower information needs.

Conclusion

People with recently diagnosed DM display high information needs, which differ according to the current level of information, mode of diabetes treatment, diabetes-related comorbidity and mental component summary score in the SF-36. There appears to be a preference for information, which can help to simplify life with diabetes and for information which corresponds to their level of knowledge. This should be considered in patient information activities.

Strengths and limitations of this study

- A strength of the present study is the ability to analyse information needs in people with recently diagnosed diabetes, a relevant patient group for the provision of suitable information.
- A large number of variables and their association with information needs could be analysed.
- A limitation is the cross-sectional design.
- Furthermore, the present observational study was not designed as a population-based study with a representative sample; for example, our cohort included more male and younger participants as well as more highly educated participants.

Introduction

Diabetes mellitus (DM) is composed of different abnormalities associated with chronic hyperglycaemia, and is characterized by complex self-management tasks (1). Patients require high-quality and evidence-based information to enable adequate decision-making (2). People with DM show a higher information need compared to people with other diseases, such as cardiovascular and respiratory diseases (3). However, despite existing efforts to improve available information and a growing discussion of associated factors such as health literacy, patients' information needs are frequently disregarded.

A recent systematic review revealed surprisingly few studies addressing the information needs of people with DM (4), in particular in people with recently diagnosed diabetes. As of today, there is only one study which analyses information needs in people with recently diagnosed diabetes (5). However, only people with type 2 diabetes were involved, and only qualitative methods were used. Several questions remain unanswered, such as whether there are differences between patient subgroups and which factors are associated with information needs.

Thus, the present study aims to identify and analyse (i) information needs of people with recently diagnosed type 1 or type 2 DM; (ii) information needs within different subgroups; and (iii) factors associated with information needs concerning DM such as current level of information, health-related quality of life or participation preferences. An information need is defined as the 'recognition that their knowledge is inadequate to satisfy a goal, within the context/situation that they find themselves at a specific point in the time' (6).

Methods

Study design and population

The present cross-sectional study combined quantitative and qualitative methods (mixed-methods) using baseline data of participants in the German Diabetes Study (GDS). GDS is an ongoing

prospective observational study initiated and coordinated by the German Diabetes Center (7). The GDS aims to investigate the course of disease and the consequences of DM, and has been described in detail elsewhere (7). Participants are people aged between 18 and 69 with recently diagnosed DM with a duration of less than 12 months of known diabetes. Data assessment comprises standardised questionnaires and interviews, detailed physical examinations and comprehensive metabolic phenotyping.

The present study included 157 consecutive participants from the GDS between February 2014 and May 2016. Nineteen participants were excluded due to missing variables, yielding 138 for the final analysis.

Ethical approval

The GDS was approved by the ethics committee of Heinrich Heine University Düsseldorf (study reference number 4508, previous reference number 2478). This study is performed according to the Declaration of Helsinki and registered at Clinicaltrials.gov (Identifier: NCT01055093) (7).

Patient and Public Involvement

Patients and public were not involved in the present study. The questionnaire for measuring the need for information was developed with the participation of people with DM in focus groups.

Assessment of information needs

Information needs were assessed using a questionnaire developed and evaluated by Chernyak *et al.* (8) (Appendix 1). The German language version has been previously applied to a clinic-based population of people with DM (8). The questionnaire is based on a mixed-methods design, namely a partially mixed concurrent equal-status design (9). Both quantitative and qualitative data were assessed without prioritising either of the methods.

It includes 11 topics of information needs (8): 'causes of diabetes', 'course of the disease', 'treatment/therapy', 'acute complications', 'late complications', 'diabetes in everyday life', 'mental strain', 'lifestyle adjustment, health promotion and prevention', 'support, helplines and information sources', 'social and legal aspects' and 'diabetes research'. Participants are able to mark whether information is currently needed (no=0 / yes=1) and assess their current level of information for each topic (very well, well, not well, not informed at all). Furthermore, participants can prioritise a maximum of three topics for which they currently need information. A blank text field is provided per information need to specify selected needs: 'Please explain what particular interests you have about these topics'. They can also add an individual unlisted information need in any question. At the end of the information needs questionnaire, the participants have the opportunity to reply to the question 'What do you consider to be particularly important with regard to information on diabetes?' in a blank text field.

Variables

Outcome: category of information need

Three categories of information needs were defined for the purposes of the present study. The first was the desire for information (no=0 / yes=1) on diabetes research. The second category focussed on topics related to clinical factors of DM including a need for information on the causes of diabetes, course of the disease, acute complications, long-term complications and mental strain. The needs identified in the third category focussed on the management and handling of DM including management-related topics, treatment/therapy, diabetes in everyday life, lifestyle adjustment, health promotion and prevention, support, helplines and information sources, and social and legal aspects. Within the second and third categories, results were summed up and dichotomised into 'low information needs' (ranging from 0 to 2) or 'high information needs' (ranging from 3 to 5).

Factors associated with information needs

The associated factors were taken from the data assessed in GDS as described above. The variables were selected as follows: firstly, a set of variables was deduced empirically from the existing literature for quantitative analysis (10–15). Studies showed that age (years), sex, education, type of diabetes, mode of diabetes treatment and health status appear to have an impact on information needs (10–15). Education was coded by 'other graduation' and 'university degree'; the type of diabetes was coded by 'type 1', 'type 2' and 'other'; mode of diabetes treatment was coded by 'no antihyperglycaemic medication', 'oral glucose-lowering drugs' and 'insulin'. Health status was defined according to diabetes-related comorbidities (nephropathy, neuropathy, peripheral arterial occlusive disease, myocardial infarction, stroke, transient ischemic attack).

Secondly, five explorative groups of thematically relevant variables in the context of diabetes were developed on a theoretical basis: (i) socio-economic factors are associated with diabetes-related information-seeking behaviour (16). Further socio-economic factors in addition to education, which has already been included, were therefore included: employment coded by 'no' or 'yes'; school graduation defined as 'other graduation' and 'graduation from high school'; and migration background, denoted by place of birth other than Germany or nationality other than German.

(ii) Past diabetes experience is associated with information needs (4). It can therefore be assumed that diabetes-related and health-related factors may have an impact on information needs. Hence, besides diabetes type and mode of diabetes treatment which have already been included, the duration of DM (time since diagnosis until inclusion in the GDS), HbA_{1c} and number of overall drugs were also included.

(iii) As some studies on information needs also report on participation preferences and on the people's knowledge (4), this variable was added. Self-reported participation preferences, and thus the wish to be involved in medical decision-making, were measured by the Control Preference Scale, coded by 'passive role', 'collaborative role' and 'active role' (17). The information needs

questionnaire included questions about current level of information. The current level of information on diabetes research was coded by 'high current level of information' (very well or well informed) and 'low current level of information' (not well or not informed at all). The other two categories of information needs were summed up and dichotomised into 'high current level of information' (ranging from 0 to 6) as well as 'low current level of information' (ranging from 7 to 15).

(iv) The fourth group of variables refers to depression and health-related quality of life. People with DM have a higher prevalence of depression and a lower health-related quality of life than people without DM (18, 19). This may lead to a lower level of activity. Depression was measured using the Center for Epidemiological Studies Depression Scale, long German version (ADS-L) (20) and Problem Areas in Diabetes (PAID) survey (21, 22). In accordance with the respective published evaluation methods, depression was coded according to ADS-L as 'clinically relevant depression' (cut-off score >22) and according to PAID as 'severe diabetes-related distress' (cut-off score ≥40). Health-related quality of life was measured using the 36-Item Short-Form Health Survey (SF-36) (23, 24) and analysed according to the physical and mental summary scales. In addition, the 5-Item World Health Organization Well-Being Index (WHO-5) questionnaire was analysed and quality of life was coded as 'low quality of life' (ranging from 0 to 12) and 'high quality of life' (ranging from 13 to 25) (25).

(v) Several studies have found that 'self-management' and 'lifestyle' are the main contents of the information needs of people with DM (4), and thus the present study sought to identify a possible association. Self-management was operationalised using three questions to be answered with yes or no: 'Do you have a health pass for diabetes?', 'Do you perform glucose self-monitoring?' and 'Have you ever participated in an education programme for people with diabetes?'. Variables that provide statements on the participants' lifestyles were included: body-mass index (BMI), smoking behaviour and leisure time activity. BMI was categorised in accordance with the World Health

Organization definition (2005) (26), smoking behaviour was coded by 'no answer', 'no' and 'yes'. Leisure time activity was operationalised according to the Baecke index (27, 28) as a summary of the variables: 'During leisure hours, I walk', 'During leisure hours, I ride a bike' and 'For how many minutes a day do you walk or ride a bike going back and forth from work, school or shopping?'.

Quantitative analysis

Firstly, descriptive summaries were obtained (depending on the distribution of the variables by frequencies, percentages, means ± standard deviations). Participants' current levels of information were described in percentages. Comparisons between the different categories of information needs were carried out using McNemar's test.

To estimate associations between the information need categories as described above and associated factors, multivariate logistic regression models were fitted, resulting in odds ratios (ORs) with 95% confidence intervals (CI) corresponding to 1 unit changes of the independent variable. Three groups of models were fitted, using the categories of information needs (high versus low) as a dependent binary variable.

The following steps were performed to select the final set of independent variables: we first included the six groups of variables described above fitting different models separately. We excluded variables due to many missing values, low impact in the regression analysis, low variation or high correlation to other covariables. Larger models were then fitted which included the independent variables of all six groups. After discussion of these models, fixed sets of independent variables including confounders were selected for the three main models. The final set of variables included: age, sex, education, mode of diabetes treatment (antihyperglycaemic medication yes versus no), diabetes-related comorbidity (binary), current level of information (high versus low),

health-related quality of life (mental and physical component summary score in the SF-36) and BMI (≥30 kg/m² versus <30 kg/m²).

With regard to the research-related information needs outcome, the corresponding model was only fitted in the subpopulation of subjects with type 2 diabetes, since all participants from the type 1 subgroup were in need of information on diabetes research. The models for the clinical and management-related information needs outcomes were run both for type 1 and type 2 diabetes. The mode of diabetes treatment was excluded for type 1 diabetes because only one participant in that subgroup did not use antihyperglycaemic medication. The data analysis for this paper was generated using SAS software, Version 9.4 (SAS Institute Inc., Cary, NC).

Qualitative analysis

The qualitative content analysis was used for the free text entries and performed according to Elo and Kyngäs (2007) (29). A coding tree was developed by two coders, and one coder analysed all entries and the other reviewed the coding. According to the questionnaire, the theoretical and deductive pre-defined information need categories were first analysed deductively. A subsequent inductive analysis was performed to determine the subcategories. The inductive analysis entailed 'open coding, creating categories and abstraction'. During that phase, the data were abstracted and described in order to define higher-order categories.

Results

Participant characteristics

Approximately 60% of the participants were male (Table 1). About half of them had a university degree, and three quarters were employed. One in eight had a migration background. More than 50% had type 2 diabetes, and about one fifth were treated without antihyperglycaemic medication.

Participants took an average of three different drugs. Diabetes-related comorbidity was present in every sixth person.

Current level of information

Most participants were not well informed or not informed at all about diabetes research (67.9%) (Figure 1). Regarding clinical topics, the majority of participants reported that they were very well or well informed about causes of diabetes (69.1%), long-term complications (68.7%), course of the disease (66.7%) and acute complications (60%). Mental strain (63.9%) was the only topic where not well informed or not informed at all constituted the majority. The majority of participants reported that they were very well or well informed about the following management-related topics: treatment/therapy (76.9%), diabetes in everyday life (64.4%), and lifestyle adjustment, health promotion and prevention (58.5%). The majority of participants stated that they were not well informed or not informed at all regarding the topics support, helplines and information sources (56.7%), and social and legal aspects (74.1%). There were more participants with a high current level of information on clinical topics (48.1%) than with a high current level of information on management-related topics (35.6%) (McNemar's test p=0.007).

Quantitative results

Information needs

When asked which topics they would like information on, the majority of participants stated a need for information on all topics listed in the questionnaire (Figure 2). Most of them (85.8%) wished to have more information about diabetes research. Of the clinical topics, participants showed the greatest need for information on the course of the disease (66.1%). The lowest need was stated for information on acute complications (60.3%) and mental strain (56.6%). Management-related topics, e.g. treatment/therapy (80.5%) and lifestyle adjustment, and health promotion and prevention

(77.9%) were generally of more interest than clinical topics. The lowest information need for management-related topics was found for support, helplines and information sources (62.9%). Four participants stated no information need.

116 participants selected three prioritised topics, whilst some participants selected only two (n=10) or one (n=5). Figure 3 shows the percentage with which each topic was selected as the priority from all possible options (relative to all 131 participants with valid data). When asked to rank the three most important topics (page one of the questionnaire, Appendix 1), participants prioritised information about diabetes research (39.7%) more than most topics allocated to the other two categories. A high information need was also reported for the clinical topics long-term complications (38.9%) and causes of diabetes (29.8%). The topics course of the disease (15.3%) and mental strain (9.9%), and especially the topic acute complications (3.8%), were rarely prioritised. The highest priority was reported for information about treatment/therapy as a management-related topic (48.1%). In the category management-related topics, high information needs were also reported for lifestyle adjustment, health promotion and prevention (38.9%), and diabetes in everyday life (32.1%). The topics support, helplines and information sources (13%), and social and legal aspects (10.7%) were rarely prioritised.

Associated factors

The multiple logistic regression models for participants with type 1 diabetes (Appendix 2a) showed that the current level of information in clinical and management-related topics is significantly associated with information needs (OR 0.17 (0.03–0.92) and 0.11 (0.02–0.75)). In people with type 1 diabetes, a higher mental component summary score in the SF-36 is significantly associated with low information needs concerning management-related topics (OR 0.87 (0.76–0.995)).

Participants with type 2 diabetes (Appendix 2b) treated with antihyperglycaemic medication were more likely to have information needs regarding diabetes research compared to those without

antihyperglycaemic medication (OR 6.98 (1.38–35.21)). Existing comorbidities in people with type 2 diabetes were associated with low information needs regarding diabetes research (OR 0.04 (0.01–0.38)). However, low statistical power should be considered in the interpretation of the non-significant results.

If a Bonferroni adjustment for multiple testing for the number of independent variables were to be considered, only the association of need for diabetes research and diabetes-related comorbidity would remain significant in subjects with type 2 diabetes.

Qualitative results

Qualitative analysis showed that participants who sought information about topics in the category diabetes research specifically expressed a need for information on study participation and results, scientific developments (especially for cures, treatment (e.g. artificial pancreas)), and technical devices (e.g. blood glucose measurement).

Specific information needs that were stated for clinical topics, such as causes of diabetes, were: causes of latent autoimmune diabetes in adults and people with type 1 diabetes in older age. Participants wanted to know more about the course of the disease, especially a description of the disease process and positive influences on the course of the disease. Wishes for information about acute complications were not explained in more detail. As far as long-term complications are concerned, participants expressed specific needs for information regarding the conditions under which these long-term complications occur, and how symptoms can be prevented and recognised. Needs for information regarding mental strain included information on the impact on daily life, stress management and fear of hypoglycaemia.

Participants who were interested in the management-related topics category expressed specific information needs about treatment/therapy, in particular information on existing and new treatment options (e.g. continuous glucose monitoring, insulin pump therapy) and information about

simplified therapy, especially with less measuring and fewer insulin syringes. Specific needs in diabetes in everyday life were: coping strategies in certain situations including tips for simplification (e.g. holidays, work), diabetes management (e.g. time management, calculating insulin or bread units) and interaction with people with DM. Information needs in the lifestyle adjustment, health promotion and prevention category included information about sports and nutrition, tips and strategies for handling diabetes better, and possibilities to share experiences (e.g. health insurance, weight-loss clinic). In the support, helplines and information sources category, participants expressed interest in an overview of existing support offers and education programs. Participants who prioritised social and legal aspects wanted information about diabetes as a disability and job-related information (e.g. terminating employment).

The results of the last open question identified a preference for information to be provided personally, in brochure and video form, or at specific information events. Patients expressed a preference for information to be provided at all times especially recently after diagnosis and when new insights are gained, and for it to be comprehensive, transparent, neutral and of high quality. Furthermore, participants expressed a wish for information to be adapted to their level of knowledge.

Synthesis of quantitative and qualitative results

The greatest level of interest was shown in the two categories diabetes research and management-related topics, particularly the topic treatment/therapy in the latter. Where diabetes research is concerned, participants requested more information on new treatments and technical devices. In both topics, there was a strong desire for information about new insights to simplify treatment. Simplification and disease management are core qualitative aspects that appear to be relevant to coping strategies in daily live. Individual characteristics such as existing knowledge appear to be

particularly relevant to information needs and information provision. It can also be noted that participants requested information to be adapted to their level of knowledge.

Discussion

Participants with recently diagnosed DM have a high information need in all the topics concerning diabetes that were assessed with the information needs questionnaire. They express a particular need for diabetes research and prefer more management-related topics than clinical topics. Information needs concerning DM seem to be associated with current level of information, mode of diabetes treatment, diabetes-related comorbidity, and mental component summary score in the SF-36.

The highest information need concerned diabetes research. This may be due to the fact that participants in the GDS are more interested in research questions than people with DM who do not participate in a research study (7, 30). The qualitative results indicate that participants wish information to be up-to-date with the latest scientific findings. Another aim could be to verify information provided by their physician (31). Other studies have also identified an interest in information on recent scientific development (4).

In general, participants requested more information on management-related topics than on clinical topics. The qualitative data clearly show that the explanation of clinical topics frequently includes management-related information. For example, participants stated that they would like to receive more information on stress management. Resource-oriented provision of information is therefore more likely to meet the needs of people with recently diagnosed diabetes. It can be assumed that this is related to the stage at which the recent diagnosis of diabetes was made and a presumably better health status. A high need for information about treatment/therapy has also been identified by other studies (5, 12, 14, 31–34).

In people with type 1 diabetes, the analysis of the two categories clinical topics and management-related topics showed that a low current level of information is associated with a higher need for information. However, despite being currently well informed, participants still required information on treatment/therapy. An explanation could be: although people feel well informed, they do not have the specific information which helps them to achieve their personal goal (for instance the simplification of everyday life). The qualitative data show that a number of participants would like more detailed information that is adapted to their level of knowledge. In contrast, information on mental strain was rarely prioritised, although a low current level of information was reported. St. Jean (2016) posited that a lack of information sources or unconscious information could account for why relevant information cannot be obtained (31). The low information need concerning mental strain may also be explained by the fact that the recently diagnosed participants do not experience mental strain.

A higher mental component summary score in the SF-36 was associated with lower information needs in management-related topics in people with type 1 diabetes. The health-related quality of life of people with type 1 diabetes is often reduced because of diabetes-related factors, for example fear of hypoglycaemia (also reported as an information need in the qualitative results) (35). In this study, people with a higher mental component summary score in the SF-36 may feel that they do not need any further information to manage their situation. Other studies show that optimistic feelings and support in diabetes experience were associated with different information needs in people with DM (4).

In people with type 2 diabetes, antihyperglycaemic medication appears to be associated with a greater need for information on diabetes research. This finding confirms a focus group analysis by Lamberts et al. (2010), which showed a greater need for drug-related information in people who have recently started treatment with oral glucose-lowering drugs (14).

Surprisingly, diabetes-related comorbidity in people with type 2 diabetes was associated with a lower need for information for diabetes research. No other study reported this association. Adjustments were made for the current level of information, but it cannot be ruled out that people with diabetes-related comorbidities are already well informed.

No associations were found between information needs and sex, age or further variables, possibly due to an insufficient statistical power to detect further significant associations.

Regarding the clinical implications of this study, results may contribute to an adjustment of the design of communication strategies and education programmes at an early stage of the disease. Some people with DM felt that they received enough information about diabetes and therefore did not attend self-management education programmes (36). An individual and patient-centred approach to building programs can increase participation.

Limitations and strengths

The present observational study was not designed as a population-based study and therefore does not claim to represent the entire German diabetes population. Rather, it seeks to reveal predictors associated with later outcomes (e.g. diabetes-associated cardiovascular complications) in specific subgroups and to unravel underlying mechanisms (37). Compared with population-based representative samples, our cohort included more male and younger participants as well as more highly educated participants. Nevertheless, anthropometric data, such as BMI, were comparable to other German or European cohorts (37). However, the selection may introduce bias because the patients who participated in the GDS were potentially more motivated, which could suggest a higher current level of information.

A limitation of the present study is its relatively low sample size and the large number of variables to be investigated as possible risk factors and confounders for information need. There is low statistical power to detect weaker associations. The results should therefore be interpreted with

caution. In the 'final models', associations might be overestimated because of data-driven selection. However, due to the low sample size, it was not possible to separate the data into two sets of training and test data for model building and validation of the final model. Furthermore, because of multiple testing in many different regression models some significant results might have occurred by chance with respect to alpha inflation. Reference is made to the effect of a possible Bonferroni adjustment in the results section.

The strengths of the present study are the possibility to analyse information needs in people with recently diagnosed diabetes, a relevant patient group for the provision of suitable information. It is noted that information needs may rise with the progression of the disease (31). The longitudinal design of GDS will allow a prospective analysis of the patients in this study. Another strength is: a large number of variables and their association with information needs could be analysed.

Conclusion

In people with recently diagnosed diabetes, there is currently a high information need for all topics concerning diabetes, especially diabetes research and management-related topics, although study participants reported a relatively high level of being informed. Participants expressed a particular need for information regarding simplification of life with diabetes and for information adapted to their level of knowledge. Information needs differ between patient groups in that information needs are associated with the current level of information, mode of diabetes treatment, diabetes-related comorbidity and mental component summary score in the SF-36. This has to be considered when patients are provided with information about their disease. An open question is how information needs might change over the course of the disease. The prospective GDS provides the opportunity to analyse this question in the future.

Author's contribution

AI, MR, JS, KM, VB, SG, SK, UL, NE, AS and JG contributed to the concept, design, and drafting of the present study. AI, SG, SK, AB, BH developed the design of the analysis. SG, AB, BH conducted formal analysis. SK and AI supervised the analysis process. SG, SK and AI contributed to the writing of the manuscript; all authors were involved in editing. All authors read and approved the final manuscript.

Data sharing statement

All available data can be obtained from the corresponding author.

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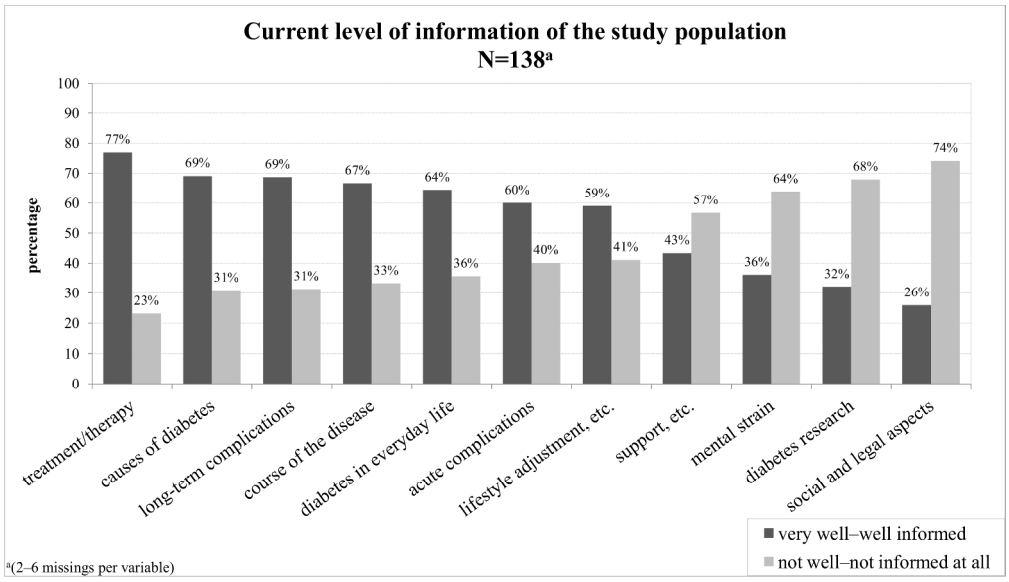
Table 1. Participants' characteristics

Characteristics		N (%)	mean (SD)
total number of participants		138	
age, n=138			46.3 (12.3)
sex, n=138	male	88 (64)	
	female	50 (36)	
university degree, n=135		64 (47)	
employment, n=137		111(81)	
migration background, n=136		18 (13)	
type of diabetes, n=138	type 1	56 (41)	
	type 2	75 (54)	
	other	7 (5)	
mode of diabetes treatment, n=130	no antihyperglycaemic medication	26 (20)	
	oral glucose-lowering drugs	51 (39)	
	insulin	50 (38)	
	oral glucose-lowering drugs and insulin	3 (2)	
number of overall drugs, n=130			2.98 (1.91)
diabetes-related comorbidity, n=136		23 (17)	

Figure 1. Current level of information of the study population on the diabetes-related topics

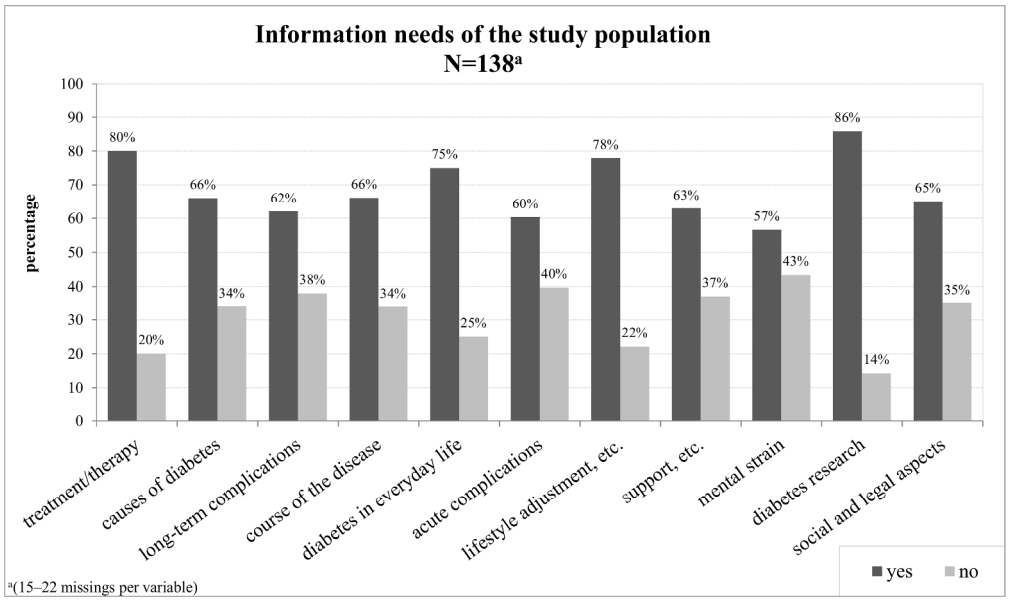
Figure 2. Information needs of the study population

Figure 3. Topics mentioned as most important by participants



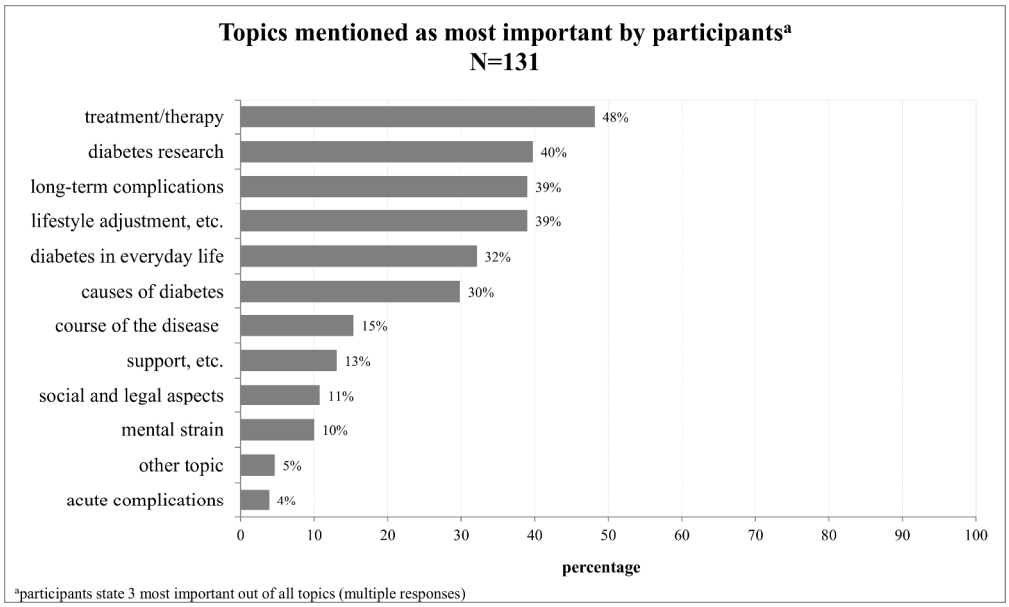
Current level of information of the study population on the diabetes-related topics

260x148mm (300 x 300 DPI)



Information needs of the study population

250x148mm (300 x 300 DPI)



Topics mentioned as most important by participants

284x169mm (300 x 300 DPI)

Appendix 1

Information Needs in Diabetes Questionnaire

1. Listed below are various topics relating to diabetes. Please have a look at this list and then consider which three topics you would currently like to have further information about. Finally, please enter these topics in the answer boxes below and explain what particular interests you have about these topics.

Topics relating to diabetes	
A	Causes of diabetes
B	Course of the disease
C	Treatment/therapy
D	Acute complications
E	Late complications
F	Diabetes in everyday life
G	Mental strain
H	Lifestyle adjustment, health promotion and prevention
I	Support, helplines and information sources
J	Social and legal aspects
K	Scientific surveys and research on diabetes
L	Other topics not included in the list

Please enter the letters representing the three topics about which you would currently like to have further information. Please explain what particularly interests you have about these topics.

Topic	**I am particularly interested in**

2. Please specify how well informed you are on the following topics and whether you currently wish to have further information on each of these topics.

How well informed are you on the following topics?					**Would you currently like information on the topic?**	
Causes of diabetes	☐ very well	☐ well	☐ not well	☐ not informed at all	☐ yes	☐ no
Course of the disease	☐ very well	☐ well	☐ not well	☐ not informed at all	☐ yes	☐ no
Treatment/therapy	☐ very well	☐ well	☐ not well	☐ not informed at all	☐ yes	☐ no
Acute complications	☐ very well	☐ well	☐ not well	☐ not informed at all	☐ yes	☐ no
Late complications	☐ very well	☐ well	☐ not well	☐ not informed at all	☐ yes	☐ no
Diabetes in everyday life	☐ very well	☐ well	☐ not well	☐ not informed at all	☐ yes	☐ no
Mental strain	☐ very well	☐ well	☐ not well	☐ not informed at all	☐ yes	☐ no
Lifestyle adjustment, health promotion and prevention	☐ very well	☐ well	☐ not well	☐ not informed at all	☐ yes	☐ no
Support, helplines and information sources	☐ very well	☐ well	☐ not well	☐ not informed at all	☐ yes	☐ no
Social and legal aspects	☐ very well	☐ well	☐ not well	☐ not informed at all	☐ yes	☐ no

How well informed are you on the following topics?					**Would you currently like information on the topic?**	
Scientific surveys and research on diabetes	☐ very well	☐ well	☐ not well	☐ not informed at all	☐ yes	☐ no
Other topics not included in the list: _____	☐ very well	☐ well	☐ not well	☐ not informed at all	☐ yes	☐ no

3. What do you consider to be particularly important with regard to information on diabetes?

_____

_____

_____

_____

_____

Appendix 2

Appendix 2a: Information needs and associated factors, results of the multivariate regression analysis, in the stratum of subjects with type 1 diabetes[1]

	Clinical-related information needs (n=41)			Management-related information needs (n=44)			Diabetes research[2]		
	OR	**95-% CI**	**p-value**	**OR**	**95-% CI**	**p-value**	**OR**	**95-% CI**	**p-value**
Socio-demographic variables									
age (years)	1.04	[0.95; 1.14]	0.366	1.07	[0.92; 1.19]	0.279	-	-	-
sex (male)	3.45	[0.63; 19.05]	0.155	5.20	[0.70; 38.83]	0.108	-	-	-
education (university degree)	3.56	[0.54; 23.30]	0.186	1.44	[0.17; 12.60]	0.741	-	-	-
Diagnosis-related variables									
diabetes-related comorbidity (yes)	0.90	[0.09; 8.98]	0.93	0.73	[0.04; 14.09]	0.836	-	-	-
Current level of information (outcome)									
current level of information (high)	0.17	[0.03; 0.92]	**0.040***	0.11	[0.02; 0.75]	**0.024***	-	-	-
Health-related quality of life									
physical component summary score (SF-36)	0.93	[0.85; 1.03]	0.175	1.05	[0.93; 1.18]	0.436	-	-	-
mental component summary score (SF-36)	0.98	[0.93; 1.04]	0.537	0.87	[0.76; 0.995]	**0.041***	-	-	-
Lifestyle									
BMI ≥30 kg/m²	3.08	[0.32; 29.98]	0.332	0.90	[0.08; 10.05]	0.934	-	-	-

[1] Covariable 'antihyperglycaemic medication' was excluded because very few people with type 1 did not use antihyperglycaemic medication
[2] The corresponding model for the outcome 'diabetes research' was instable because all people with type 1 diabetes were in need of diabetes research
*significant results ($p<0.05$)
OR= odds ratio (in age and SF-36 scores corresponding to one unit change)
CI= confidence intervals
SF-36= 36-Item Short-Form Health Survey
BMI= body-mass index

Appendix 2b: Information needs and associated factors, results of the multivariate regression analysis, in the stratum of subjects with type 2 diabetes

	Clinical-related information needs (n=55)			Management-related information needs (n=53)			Diabetes research (n=56)		
	OR	**95-% CI**	**p-value**	**OR**	**95-% CI**	**p-value**	**OR**	**95-% CI**	**p-value**
Socio-demographic variables									
age (years)	1.04	[0.97; 1.12]	0.296	1.05	[0.96; 1.15]	0.300	1.01	[0.92; 1.11]	0.801
sex (male)	0.82	[0.19; 3.60]	0.794	0.59	[0.09; 3.72]	0.573	0.43	[0.07; 2.61]	0.358
education (university degree)	0.42	[0.11; 1.67]	0.218	1.18	[0.24; 5.78]	0.842	0.82	[0.18; 3.77]	0.804
Diagnosis-related variables									
antihyperglycaemic medication (yes)	0.82	[0.20; 3.47]	0.790	1.63	[0.30; 8.96]	0.576	6.98	[1.38; 35.21]	**0.019***
diabetes-related comorbidity (yes)	0.73	[0.12; 4.32]	0.725	0.22	[0.03; 1.58]	0.133	0.04	[0.01; 0.38]	**0.004***
Current level of information (outcome)									
current level of information (high)	0.42	[0.11; 1.66]	0.214	0.28	[0.05; 1.72]	0.171	1.84	[0.31; 10.84]	0.503
Health-related quality of life									
physical component summary score (SF-36)	0.98	[0.93; 1.03]	0.447	1.01	[0.95; 1.08]	0.731	0.96	[0.90; 1.03]	0.270
mental component summary score (SF-36)	1.00	[0.93; 1.07]	0.997	0.99	[0.92; 1.07]	0.804	1.04	[0.96; 1.13]	0.342
Lifestyle									
BMI ≥30 kg/m²	0.36	[0.09; 1.44]	0.148	2.55	[0.51; 12.89]	0.257	0.63	[0.14; 2.84]	0.551

*significant results (p<0.05)
OR= odds ratio (in age and SF36 scores corresponding to one unit change)
CI= confidence intervals
SF-36= 36-Item Short-Form Health Survey
BMI= body-mass index