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

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Complete List of Authors:	<p>Grobosch, Sandra; German Diabetes Center, Leibniz Center for Diabetes Research at Heinrich Heine University, Institute of Health Services Research and Health Economics; Heinrich Heine University Düsseldorf, Institute of Health Services Research and Health Economics, Centre for Health and Society, Faculty of Medicine</p> <p>Kuske, Silke; German Diabetes Center, Leibniz Center for Diabetes Research at Heinrich Heine University, Institute of Health Services Research and Health Economics; Heinrich Heine University Düsseldorf, Institute of Health Services Research and Health Economics, Centre for Health and Society, Faculty of Medicine</p> <p>Linnenkamp, Ute; German Diabetes Center, Leibniz Center for Diabetes Research at Heinrich Heine University, Institute of Health Services Research and Health Economics</p> <p>Ernstmann, Nicole ; University Hospital of Bonn, Center for Health Communication and Health Services Research, Department for Psychosomatic Medicine and Psychotherapy</p> <p>Stephan, Astrid; Heinrich Heine University Düsseldorf, Institute of Health Services Research and Health Economics</p> <p>Genz, Jutta; German Diabetes Center, Leibniz Center for Diabetes Research at Heinrich Heine University, Institute for Biometrics and Epidemiology</p> <p>Begun, Alexander; German Diabetes Center, Leibniz Center for Diabetes Research at Heinrich Heine University, Institute of Health Services Research and Health Economics; German Diabetes Center, Leibniz Center for Diabetes Research at Heinrich Heine University, Institute for Biometrics and Epidemiology</p> <p>Haastert, Burkhard; Heinrich Heine University Düsseldorf, Institute of Health Services Research and Health Economics, Centre for Health and Society, Faculty of Medicine; mediStatistica</p> <p>Szendroedi, Julia; Heinrich Heine University Düsseldorf, Department of Endocrinology and Diabetology, Faculty of Medicine; German Diabetes Center, Leibniz Center for Diabetes Research at Heinrich Heine University, Institute for Clinical Diabetology</p> <p>Müssig, Karsten; Heinrich Heine University Düsseldorf, Department of Endocrinology and Diabetology, Faculty of Medicine; German Diabetes Center, Leibniz Center for Diabetes Research at Heinrich Heine University, Institute for Clinical Diabetology</p> <p>Burkart, Volker; German Diabetes Center, Leibniz Center for Diabetes Research at Heinrich Heine University, Institute for Clinical Diabetology; German Center for Diabetes Research (DZD)</p> <p>Roden, Michael; Heinrich Heine University Düsseldorf, Department of</p>

	Endocrinology and Diabetology, Faculty of Medicine; German Diabetes Center, Leibniz Center for Diabetes Research at Heinrich Heine University, Institute for Clinical Diabetology Icks, Andrea; German Diabetes Center, Leibniz Center for Diabetes Research at Heinrich Heine University, Institute of Health Services Research and Health Economics; Heinrich Heine University Düsseldorf, Institute of Health Services Research and Health Economics, Centre for Health and Society, Faculty of Medicine
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2 1 Information needs of people with recently diagnosed diabetes mellitus: results from
3 2 the German Diabetes Study.
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6 5 Sandra Grobosch^{1,2,*}, Silke Kuske^{1,2,*}, Ute Linnenkamp¹, Nicole Ernstmann³, Astrid Stephan²,
7 6 Jutta Genz⁴, Alexander Begun^{1,4}, Burkhard Haastert^{2,5}, Julia Szendroedi^{6,7,8}, Karsten
8 7 Müssig^{6,7,8}, Volker Burkart^{7,8}, Michael Roden^{6,7,8,Z}, Andrea Icks^{1,2,8,Z} and the GDS Group**
9 8
10 9

11 10 Sandra Grobosch*, BSc.,

12 11 1Institute of Health Services Research and Health Economics, German Diabetes Center, Leibniz
13 12 Center for Diabetes Research at Heinrich Heine University, Düsseldorf, Germany

14 13 2Institute of Health Services Research and Health Economics, Centre for Health and Society,
15 14 Faculty of Medicine, Heinrich Heine University Düsseldorf, Germany
16 15

17 16 Silke Kuske*, Prof.,

18 17 1Institute of Health Services Research and Health Economics, German Diabetes Center, Leibniz
19 18 Center for Diabetes Research at Heinrich Heine University, Düsseldorf, Germany

20 19 2Institute of Health Services Research and Health Economics, Centre for Health and Society,
21 20 Faculty of Medicine, Heinrich Heine University Düsseldorf, Germany
22 21

23 22 Ute Linnenkamp, EMPH

24 23 1Institute of Health Services Research and Health Economics, German Diabetes Center, Leibniz
25 24 Center for Diabetes Research at Heinrich Heine University, Düsseldorf, Germany
26 25

27 26 Nicole Ernstmann, Prof.

28 27 3Center for Health Communication and Health Services Research, Department for Psychosomatic
29 28 Medicine and Psychotherapy, University Hospital of Bonn, Bonn, Germany
30 29

31 30 Astrid Stephan, Dr.

32 31 2Institute of Health Services Research and Health Economics, Centre for Health and Society,
33 32 Faculty of Medicine, Heinrich Heine University Düsseldorf, Germany
34 33

35 34 Jutta Genz, MA.

36 35 4Institute for Biometrics and Epidemiology, German Diabetes Center, Leibniz Center for Diabetes
37 36 Research at Heinrich Heine University, Düsseldorf, Germany
38 37

39 38 Alexander Begun, Dipl.

40 39 1Institute of Health Services Research and Health Economics, German Diabetes Center, Leibniz
41 40 Center for Diabetes Research at Heinrich Heine University, Düsseldorf, Germany

42 41 4Institute for Biometrics and Epidemiology, German Diabetes Center, Leibniz Center for Diabetes
43 42 Research at Heinrich Heine University, Düsseldorf, Germany
44 43

45 44 Burkhard Haastert, Dr.

46 45 2Institute of Health Services Research and Health Economics, Centre for Health and Society,
47 46 Faculty of Medicine, Heinrich Heine University Düsseldorf, Germany

48 47 5mediStatistica, Neuenrade, Germany
49 48

50 49 Julia Szendroedi, Dr.
51 50
52 51
53 52
54 53
55 54
56 55
57 56
58 57
59 58
60 59

1 50 6Department of Endocrinology and Diabetology, Faculty of Medicine, Heinrich Heine University,
2 51 Düsseldorf, Germany
3
4 52 7Institute for Clinical Diabetology, German Diabetes Center, Leibniz Center for Diabetes Research
5 53 at Heinrich Heine University, Düsseldorf, Germany
6 54 8German Center for Diabetes Research (DZD), Munich-Neuherberg, Germany
7 55

8 56 Karsten Müssig, Prof.

9 57 6Department of Endocrinology and Diabetology, Faculty of Medicine, Heinrich Heine University,
10 58 Düsseldorf, Germany
11
12 59 7Institute for Clinical Diabetology, German Diabetes Center, Leibniz Center for Diabetes Research
13 60 at Heinrich Heine University, Düsseldorf, Germany
14 61 8German Center for Diabetes Research (DZD), Munich-Neuherberg, Germany
15 62

16 63 Volker Burkart, PD Dr.

17 64 7Institute for Clinical Diabetology, German Diabetes Center, Leibniz Center for Diabetes Research
18 65 at Heinrich Heine University, Düsseldorf, Germany
19 66 8German Center for Diabetes Research (DZD), Munich-Neuherberg, Germany
20 67

21 68 Michael Roden, Prof., Z

22 69 6Department of Endocrinology and Diabetology, Faculty of Medicine, Heinrich Heine University,
23 70 Düsseldorf, Germany
24 71 7Institute for Clinical Diabetology, German Diabetes Center, Leibniz Center for Diabetes Research
25 72 at Heinrich Heine University, Düsseldorf, Germany
26 73 8German Center for Diabetes Research (DZD), Munich-Neuherberg, Germany
27 74

28 75 Andrea Icks, Prof., Z

29 76 1Institute of Health Services Research and Health Economics, German Diabetes Center, Leibniz
30 77 Center for Diabetes Research at Heinrich Heine University, Düsseldorf, Germany
31 78 2Institute of Health Services Research and Health Economics, Centre for Health and Society,
32 79 Faculty of Medicine, Heinrich Heine University Düsseldorf, Germany
33 80 8German Center for Diabetes Research (DZD), Munich-Neuherberg, Germany
34 81

35 82 The GDS Group**

36 83 ** The GDS Group consists of M. Roden (speaker), H. Al-Hasani, A. E. Buyken, J. Eckel, G.
37 84 Geerling, C. Herder, A. Icks, J. Kotzka, O. Kuß, E. Lammert, D. Markgraf, K. Müssig, W.
38 85 Rathmann, J. Szendrödi, D. Ziegler and their co-workers who are responsible for the design and
39 86 conduct of the GDS.
40 87

41 88 * These authors contributed equally to this work (shared first authorship).

42 89 Z shared senior authorship
43 90

44 91 Corresponding author:

45 92 Sandra Grobosch
46 93 Auf'm Hennekamp 65
47 94 40225 Düsseldorf, Germany
48 95 sandra.grobosch@ddz.uni-duesseldorf.de
49 96
50 97
51 98

1
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3

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12 108

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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

1 138 People with recently diagnosed DM present with high information needs, which differ with respect
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4 139 to the level of current information, mode of diabetes treatment and diabetes-related comorbidity.
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6 140 This should be considered in patient information activities.
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8 141

10 142 **Strengths and limitations of this study**

- 13 143 • A strength of the study is the possibility to analyze information needs in patients with recently
14
15 144 diagnosed diabetes, a relevant patient group for the provision of suitable information.
- 17
18 145 • We were able to analyze a large number of variables as possible risk factors and confounders for
19
20 146 information needs.
- 22 147 • A limitation is the cross-sectional design.
- 24
25 148 • Further, this observational study was not designed as a population-based study with a
26
27 149 representative sample; for example, our cohort included more male and younger as well as more
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29 150 highly educated participants.
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151 **Introduction**

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

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

170 Surprisingly, there is a lack of studies addressing the information needs of people with DM, in
171 particular in people with recently diagnosed diabetes. As of today, there is only one study analyzing
172 information needs in patients with recently diagnosed diabetes (9). However, only people with type
173 2 diabetes were involved, and only qualitative methods were used. Several questions remain
174 without answers, such as whether there are differences between patient subgroups, and which
175 factors are associated with information needs.

1 176 Thus, this study aims to identify and analyze (i) information needs of people with recently
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4 177 diagnosed type 1 as well as type 2 DM; (ii) information needs within different subgroups; and (iii)
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6 178 factors or concepts associated with information needs concerning DM such as level of current
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8 179 information, quality of life or participation preferences.
9

13 181 **Methods**

15 182 **Study design and population**

17 183 This cross-sectional study combined quantitative and qualitative methods (mixed methods) using
18
19
20 184 baseline data of participants in the German Diabetes Study (GDS). GDS is an ongoing prospective
21
22 185 multi-center observational study, which was initiated and is coordinated by the German Diabetes
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24 186 Center (10). This study aims to investigate the course of disease and the consequences of DM, and
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26
27 187 has been described in detail elsewhere (10). Briefly, participants are 18- to 69-year-old people with
28
29 188 recently diagnosed DM with a duration of less than 12 months of known diabetes. Data assessment
30
31 189 comprises standardized questionnaires and interviews, detailed physical examinations and
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33
34 190 comprehensive metabolic phenotyping.

35
36 191 The present analysis included 157 consecutive participants in GDS between February 2014 and
37
38 192 May 2016. Nineteen participants were excluded due to missing variables, yielding 138 for the final
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40
41 193 analysis.

45 195 **Assessment of information needs**

46
47 196 Information needs were assessed using a questionnaire developed and evaluated by Chernyak *et al.*
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50 197 The German language version has been previously applied to a clinic-based population of people
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52 198 with DM (11). This questionnaire is based on a mixed-methods design (11), a partially mixed
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54 199 concurrent equal-status design, assessing both quantitative and qualitative data (12), without
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56
57 200 prioritizing either of the methods.

1 201 It includes 11 topics of information needs (11): ‘causes of diabetes’, ‘course of the disease’,
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4 202 ‘treatment/therapy’, ‘acute complications’, ‘late complications’, ‘diabetes in everyday life’, ‘mental
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6 203 strain’, ‘lifestyle adjustment, health promotion and prevention’, ‘support, helplines and information
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8 204 sources’, ‘social and legal aspects’ and ‘diabetes research’. Patients were able to mark for each
9
10 205 topic if information is currently needed (no=0 / yes=1), and prioritize a number of the main
11
12 206 information needs topics. Furthermore, patients stated for each topic how well they regard their
13
14 207 personal information level (very well, well, not well, not informed at all). Additionally, they could
15
16 208 add an individual unlisted information need. A blank text field was provided per information need
17
18 209 to specify selected needs: ‘Please explain what particular interests you have about these topics’. At
19
20 210 the end of the information needs questionnaire, the participants had the opportunity to reply to the
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22 211 question ‘What do you consider to be particularly important with regard to information on
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24 212 diabetes?’ in a blank text field.
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31 214 **Variables**

32 215 *Outcome information needs*

33
34 216 Three categories of information were defined. The first was the wish for information (no=0 / yes=1)
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36 217 on diabetes research. The second category, clinical topics, included causes of diabetes, course of the
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38 218 disease, acute complications, long-term complications and mental strain, and focused topics related
39
40 219 to clinical factors of DM. The third category, management-related topics, combined the topics
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42 220 treatment/therapy, diabetes in everyday life, lifestyle adjustment, health promotion and prevention,
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44 221 support, helplines and information sources, and social and legal aspects, and focused on
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46 222 management or handling of DM. Within the second and third categories, results were summed up
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48 223 and dichotomized to ‘low information needs’ (ranging from 0 to 2) as well as ‘high information
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50 224 needs’ (ranging from 3 to 5).
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1 226 *Associated factors of information needs*

2 227 The information needs questionnaire included questions about level of current information.

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4 228 According to the coding of information needs, answers to the topics of categories two and three

5
6 229 were summed up and dichotomized to ‘high level of current information’ (ranging from 0 to 6) as

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8 230 well as ‘low level of current information’ (ranging from 7 to 15).

9
10 231 The further associated factors were taken from the data assessed in GDS as described above. First, a

11 232 set of variables was selected from the literature for quantitative analysis (13–18). Studies showed

12
13 233 that age (years), sex, education, type of diabetes, mode of diabetes treatment and health status seem

14
15 234 to have an impact on information needs (13–18). Education was coded by ‘other graduation’ and

16
17 235 ‘university degree’; the type of diabetes was coded by ‘type 1’, ‘type 2’ and ‘other’ (not included in

18 236 regression analysis); mode of diabetes treatment was coded by ‘no drugs’, ‘oral glucose-lowering

19
20 237 drugs’ and ‘insulin’. Health status was operationalized by diabetes-related comorbidities

21
22 238 (nephropathy, neuropathy, peripheral arterial occlusive disease, myocardial infarction, stroke,

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24 239 transient ischemic attack).

25
26 240 Second, a set of explorative variables was selected: employment coded by ‘no’ or ‘yes’; school

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28 241 graduation operationalized by ‘other graduation’ and ‘graduation from high school’; and migration

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30 242 background, operationalized by place of birth other than Germany or nationality other than German.

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32 243 Regarding DM, the duration (time at the beginning to survey time), HbA_{1c} and number of overall

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34 244 drugs were included.

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36 245 Self-reported participation preferences, and thus the wish to be involved in medical decision

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38 246 making, were measured by the Control Preference Scale, coded by ‘passive role’, ‘collaborative

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40 247 role’ and ‘active role’ (19). Depression was measured with the instruments Center for

41
42 248 Epidemiological Studies Depression Scale, long German version (ADS-L) (20) and Problem Areas

43
44 249 in Diabetes (PAID) survey (21, 22). In relation to the respective published evaluation methods, we

45
46 250 coded depression within ADS-L by ‘clinically relevant depression’ and within PAID by ‘severe

1 diabetes-related distress'. Quality of life was measured with the 36-Item Short-Form Health Survey
2 (SF-36) (23, 24), analyzed by the physical and mental summary scales. In addition, the 5-Item
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4 World Health Organization Well-Being Index (WHO-5) questionnaire was analyzed, and quality of
5
6 life was coded by 'low quality of life' and 'high quality of life' (25).
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10 Self-management was operationalized using three questions to be answered with yes or no: 'Do you
11 have a health pass for diabetes?', 'Do you perform glucose self-monitoring?' and 'Have you ever
12
13 participated in an education program for people with diabetes?'. We included variables that allow
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15 statements on the lifestyle of the participants: body-mass index (BMI), smoking behavior and
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17 leisure time activity. BMI was categorized as defined by the World Health Organization (2005)
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19 (26), smoking behavior was coded by 'no answer', 'no' and 'yes'. Leisure time activity was
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21 operationalized by the Baecke index (27, 28), as a summary of the variables: 'During leisure hours,
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23 I walk', 'During leisure hours, I ride a bike' and 'For how many minutes a day do you walk or ride
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25 a bike going back and forth from work, school or shopping?'.
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31 32 33 **Quantitative analysis** 34

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36 First, the descriptive analyses were performed (depending on the distribution of the variables by
37
38 frequencies, percentages, means \pm standard deviations). To estimate associations between the
39
40 information need categories as described above and associated factors, multivariate logistic
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42 regression models were fitted. Three groups of models were fitted, using as dependent binary
43
44 variable the need for information on diabetes research, clinical topics and management-related
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46 topics. Different models were fitted including different groups of independent variables: level of
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48 current information, age, sex, education, type of diabetes, mode of diabetes treatment, diabetes-
49
50 related comorbidity, employment, school graduation, migration background, duration of diabetes,
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52 HbA_{1c}, number of overall drugs, participation preferences, depression, quality of life, self-
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54 management and lifestyle (BMI, smoking behavior, leisure time activity). Finally, variables were
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1
2 276 selected with regard to medical and statistical aspects; three final models (one per outcome) of
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4 277 similar structure are presented summarizing the analyses. The odds ratios (ORs) were calculated
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6 278 with a 95 % confidence interval (CI). We used SAS version 9.4 for all analyses.
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8 279

10 280 **Qualitative analysis**

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13 281 The qualitative content analysis was used for the free text entries and performed according to Elo
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15 282 and Kyngäs (2007) (29). One coder analyzed all entries and the other one reviewed the codings. A
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17 283 coding tree was developed. According to the questionnaire, the theoretical and deductive pre-
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19 284 defined information need categories were analyzed first deductively, added by inductive analysis
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21 285 process of developing subcategories. We analyzed the data several times to concretize the codings
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23 286 of information needs. Performing the inductive analysis, we started with ‘open coding, creating
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25 287 categories and abstraction’. In this phase, we reduced and described the material with formulate
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27 288 higher-order categories.
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33 290 **Results**

34 291 *Participant Characteristics*

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39 292 About 60 % of the participants were male (table 1). About half of them had a university degree, and
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41 293 three quarters were employed. One in ten had a migration background. More than 50 % had type 2
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43 294 diabetes, and about one fifth were treated without drugs. Participants took an average of three
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45 295 different drugs. Diabetes-related comorbidity was present in every sixth person.
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50 297 *Level of current information*

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53 298 Most participants were not well informed or not informed at all about the category diabetes research
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55 299 (n=91) (figure 1). In terms of clinical topics, the majority of participants reported that they were
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1 300 very well or well informed about causes of diabetes (n=94), long-term complications (n=92), course
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4 301 of the disease (n=88) and acute complications (n=81). Not well informed or not informed at all
5
6 302 constituted the majority only for the topic mental strain (n=85). The majority of participants
7
8 303 reported that they were very well or well informed about the following management-related topics:
9
10 304 treatment/therapy (n=103), diabetes in everyday life (n=87), and lifestyle adjustment, health
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12 305 promotion and prevention (n=79). Not well informed or not informed at all constituted the majority
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14 306 for the topics support, helplines and information sources (n=76), and social and legal aspects
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16 307 (n=100). There were more participants with a high level of current information on clinical topics
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18 308 (n=62) than with a high level of current information on management-related topics (n=47)
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20 309 (McNemar's test p=0.007).
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27 311 ***Quantitative results***

28 29 312 *Information needs*

30
31 313 The majority of participants wished to gain information in all provided topics of the questionnaire
32
33 314 (figure 2). Most of them (n=103) wished to have more information about the category diabetes
34
35 315 research. With regards to clinical topics, the participants showed the highest need for information
36
37 316 on course of the disease (n=80). The lowest need was mentioned for information on acute
38
39 317 complications (n=73) and mental strain (n=69). Management-related topics, e.g. treatment/therapy
40
41 318 (n=99) and lifestyle adjustment, and health promotion and prevention (n=95), were generally more
42
43 319 desired than clinical topics. The lowest information need for management-related topics was
44
45 320 presented in support, helplines and information sources (n=73). Four participants reported no
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47 321 information need.
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52 322 The participants prioritized information about diabetes research (n=52) more than most topics
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54 323 allocated to the other two categories. A high information need was also reported for the clinical
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56 324 topics long-term complications (n=51) and causes of diabetes (n=40). The topics course of the
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1 325 disease (n=21) and mental strain (n=13) were rarely prioritized, especially the topic acute
2 326 complications (n=5). The highest priority was reported for information about treatment/therapy as a
3
4 326 management-related topic. In the category management-related topics, high information needs were
5
6 327 also reported for lifestyle adjustment, health promotion and prevention (n=51), and diabetes in
7
8 328 everyday life (n=42). The topics support, helplines and information sources (n=17), and social and
9
10 329 legal aspects (n=14) were rarely prioritized.
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14 15 331 16 17 332 *Associated factors and concepts*

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19
20 333 Multivariate logistic regression analyses were performed using information needs (high versus low)
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22 334 in diabetes research, clinical topics and management-related topics separately. After discussion of
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24 335 the results of models using different groups of covariables, the following fixed sets of independent
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26 336 variables including confounders were selected for the three main models: Level of current
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28 337 information (high versus low), age, sex, education, mode of diabetes treatment (insulin, oral
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30 338 glucose-lowering drugs), diabetes-related comorbidity (binary), quality of life (SF-36 physical and
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32 339 mental score) and BMI (>30 kg/m² versus ≤ 30 kg/m²). The models were fitted after excluding
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34 340 patients with missing values in one of the variables in the model (outcome diabetes research:
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36 341 n=105, clinical topics: n=99 and management-related topics: n=100).
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41 342 The level of current information, mode of diabetes treatment and diabetes-related comorbidity, are
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43 343 significantly associated with information needs: Participants, who reported high levels of
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45 344 information in clinical and management-related topics, were more likely to show a low information
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47 345 need in clinical as well as in management-related topics (OR with 95 % CIs: 0.33 (0.13–0.84) and
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49 346 0.31 (0.10–0.91)). Participants treated with oral glucose-lowering drugs or insulin were more likely
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51 347 to have information needs regarding diabetes research compared to those without drug treatment
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53 348 (8.22 (1.61–41.82) and 56.1 (2.67–1178.7)). Existing comorbidities were associated with low
54
55 349 information needs regarding diabetes research (0.05 (0.01–0.34)). The other factors (age, sex,
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1 350 education, type of diabetes, employment, school graduation, migration background, duration of
2
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4 351 diabetes, HbA_{1c}, number of overall drugs, participation preferences, depression, quality of life, self-
5
6 352 management, BMI, smoking behavior and leisure time activity) were not significantly associated
7
8 353 with information needs; however, low power should be considered in the interpretation of the non-
9
10
11 354 significant results.

15 356 *Qualitative results*

17 357 Qualitative analysis showed that participants who wished to have information about topics in the
18
19
20 358 category diabetes research mentioned as specific needs information about study participation and
21
22 359 results, scientific progress especially for cure, treatment (e.g. artificial pancreas) and technical
23
24 360 devices (e.g. blood glucose measurement).

26
27 361 Specific information needs that were stated for clinical topics, such as causes of diabetes, were:
28
29 362 causes of latent autoimmune diabetes in adults and people with type 1 diabetes at higher age.
30
31 363 Participants wanted to know more about course of disease, especially with regard to a description of
32
33 364 the disease process and positive influences on the course of the disease. Wishes for information
34
35 365 about acute complications were not explained in more detail. Concerning long-term complications,
36
37 366 participants mentioned information regarding conditions under which these occur, and prevention
38
39 367 and recognition of symptoms as specific needs. Mental strain information needs were reported as
40
41 368 the impact on daily life, stress management and fear of hypoglycemia.

44
45 369 Participants who were interested in the topics in the category management-related topics and desire
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47 370 information about treatment/therapy mentioned as specific needs: information on existing and new
48
49 371 treatment options (e.g. continuous glucose monitoring, insulin pump therapy) and information about
50
51 372 a simplified therapy, especially with less measuring and fewer insulin syringes. Specific needs in
52
53 373 diabetes in everyday life were: coping strategies in certain situations using tips for simplification
54
55 374 (e.g. holidays, work), diabetes management (e.g. time management, calculating insulin or bread
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1 375 units) and exchanges with people with DM. Information needs in lifestyle adjustment, health
2 376 promotion and prevention included interest in information about sports and nutrition, tips and
3
4 376 strategies for a better handling of diabetes, as well as possibilities for exchanging experiences (e.g.
5
6 377 health insurance, weight-loss clinic). In support, helplines and information sources, participants
7
8 378 wished for an overview of existing support offers and education programs. Participants who
9
10 379 prioritized social and legal aspects wanted information about diabetes as a disability and job-related
11
12 380 information (e.g. termination).
13
14 381

15 382 The results of the last open question showed that it is preferred when information is provided
16
17 383 personally, in form of a brochure and videos, or in specific information events. Information should
18
19 384 always be provided over time, especially recently after diagnosis and when new insights become
20
21 385 known. Information should be comprehensive, transparent, neutral and of high quality. In addition,
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23 386 the participants expressed the wish that information be adapted to their level of knowledge.
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31 388 *Synthesis of quantitative and qualitative results*

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33 389 The topic with the highest interest was diabetes research, and with regard to the category
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35 390 management-related topics particularly the topic treatment/therapy. Concerning diabetes research,
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37 391 participants wanted more information on new treatments and technical devices. In both topics, there
38
39 392 was a strong desire for information about new insights to simplify treatment. In particular,
40
41 393 individual characteristics, such as existing knowledge, seem to be relevant regarding information
42
43 394 needs and information provision. Simplification and disease management are qualitative core
44
45 395 aspects that seem to be relevant in the context of coping strategies in daily live and regarding
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47 396 further information needs, as well as regarding information behavior as information sources and
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49 397 information provision.
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56 399 **Discussion**

1
2 400 Participants with recently diagnosed DM have a high information need in all topics concerning
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4 401 diabetes that were assessed with the information needs questionnaire. They need information related
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6 402 to diabetes research and prefer more management-related topics than clinical topics. Information
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8 403 needs concerning DM seem to be associated with level of current information, mode of diabetes
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10
11 404 treatment, and diabetes-related comorbidity.

12
13 405 The highest information need addressed diabetes research. This may be due to the fact that our
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15 406 participants who participate in the GDS are more interested in research questions than people with
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17 407 DM who do not participate in a research study (10, 30). The interest in information on recent
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19
20 408 science progress has also been reported in another study (8).

21
22 409 In general, participants desired more information on management-related topics than on clinical
23
24 410 topics. It can be assumed that this is related to the stage at which the recent diagnosis of diabetes
25
26
27 411 was made and a presumably better health status. A high need for information about
28
29 412 treatment/therapy has also been found in other studies (8, 9, 13, 17, 31–34).

30
31 413 The analysis of the two categories clinical topics and management-related topics showed that a low
32
33 414 level of current information is associated with a higher need for information. However, information
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36 415 is required with regard to treatment/therapy, despite a high level of current information. In contrast,
37
38 416 information on mental strain was rarely prioritized, although a low level of current information was
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40
41 417 reported. St. Jean (2016) reported a possible lack of information sources or unconscious
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43 418 information needs as reasons that relevant information cannot be obtained (8).

44
45 419 Pharmaceutical diabetes treatment seems to be associated with a higher need for information on
46
47 420 diabetes research. This finding confirms a focus group analysis by Lamberts et al. (2010), which
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50 421 showed a higher information need for drug-related information in people who have recently started
51
52 422 treatment with oral glucose-lowering drugs (17).

1 423 Surprisingly, diabetes-related comorbidity was associated with a lower information need in diabetes
2
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4 424 research. No other study reported this association. We adjusted for the current level of information,
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6 425 but we cannot exclude that people with diabetes-related comorbidities are already well informed.
7

8 426 We found no associations between information needs and sex, age, sociodemographic or further
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10
11 427 variables, possibly due to an insufficient power to detect further significant associations.
12

13 428

14

15 429 *Limitations and strengths*

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17 430 This observational study was not designed as a population-based study and therefore does not claim
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20 431 to represent the total German diabetes population, but intends to reveal predictors associated with
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22 432 later outcomes in specific subgroups and to unravel underlying mechanisms (35). Compared with
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25 433 population-based representative samples, our cohort included more male and younger as well as
26
27 434 more highly educated participants. Nevertheless, anthropometric data, such as BMI, were
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29 435 comparable to other German or European cohorts (35). Furthermore, bias introduced by referral of
30
31 436 possibly more motivated patients needs to be considered. Of note, one might suggest a higher level
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34 437 of information in such patients.
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36 438 A limitation of the study is its relatively low sample size and a large number of variables to be
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38 439 investigated as possible risk factors and confounders for information need. There is low power to
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40
41 440 detect weaker associations. The results should therefore be interpreted with caution. In the ‘final
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43 441 models’, associations might be overweighted because of data-driven selection. Due to the low
44
45 442 sample size it was not possible to separate the data into two sets of training and test data for model
46
47 443 building and validating the final model. Furthermore, no adjustment for multiple testing was
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49
50 444 performed.
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52 445 The strengths of the study are the possibility to analyze information needs in patients with recently
53
54 446 diagnosed diabetes, a relevant patient group for the provision of suitable information. Of note,
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1
2 447 information needs may rise with the progression of the disease (8). The longitudinal design of GDS
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4 448 will allow a prospective analysis of the patients in this study.
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6 449

8 450 **Conclusion**

9
10 451 In people with recently diagnosed diabetes, there is currently a high information need for all topics
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12 452 concerning diabetes, especially diabetes research and management-related topics. Information needs
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14 453 differ between patient groups in that information needs are associated with the level of current
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16
17 454 information, mode of diabetes treatment and diabetes-related comorbidity. This has to be considered
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19 455 when patients are provided with information about their disease. An open question is how
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22 456 information needs might change during the course of disease. The prospective GDS provides the
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24 457 opportunity to analyze this question in the future.
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1 **Author's contribution**

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3
4 AI, MR, JS, KM, VB, SG, SK, NE, AS, JG and GDS Group contributed to the concept, design, and drafting of the
5
6 pilot study. AI, SG, SK, AB, BH developed the design of the analysis. SG, AB, BH conducted formal analysis. SK
7
8 and AI supervised the process of analysis. SG, SK and AI made contributions to the write-up the manuscript and
9
10 all authors to edit it. All authors read and approved the final manuscript.
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15 **Data Sharing Statement**

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17 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 female	88 (64) 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 type 2 other	56 (41) 75 (54) 7 (5)
mode of diabetes treatment, n=130	no drugs oral glucose-lowering drugs insulin oral glucose-lowering drugs and insulin	26 (20) 51 (39) 50 (38) 3 (2)
number of overall drugs, n=130		2.98 (1.91)
diabetes-related comorbidity, n=136		23 (17)

1 *Figure 1. Level of current information of the study population on the diabetes-related topics (2–6 missings per variable)*
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4 *Figure 2. Information needs of the study population (15–22 missings per variable)*
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For peer review only

Figure 1

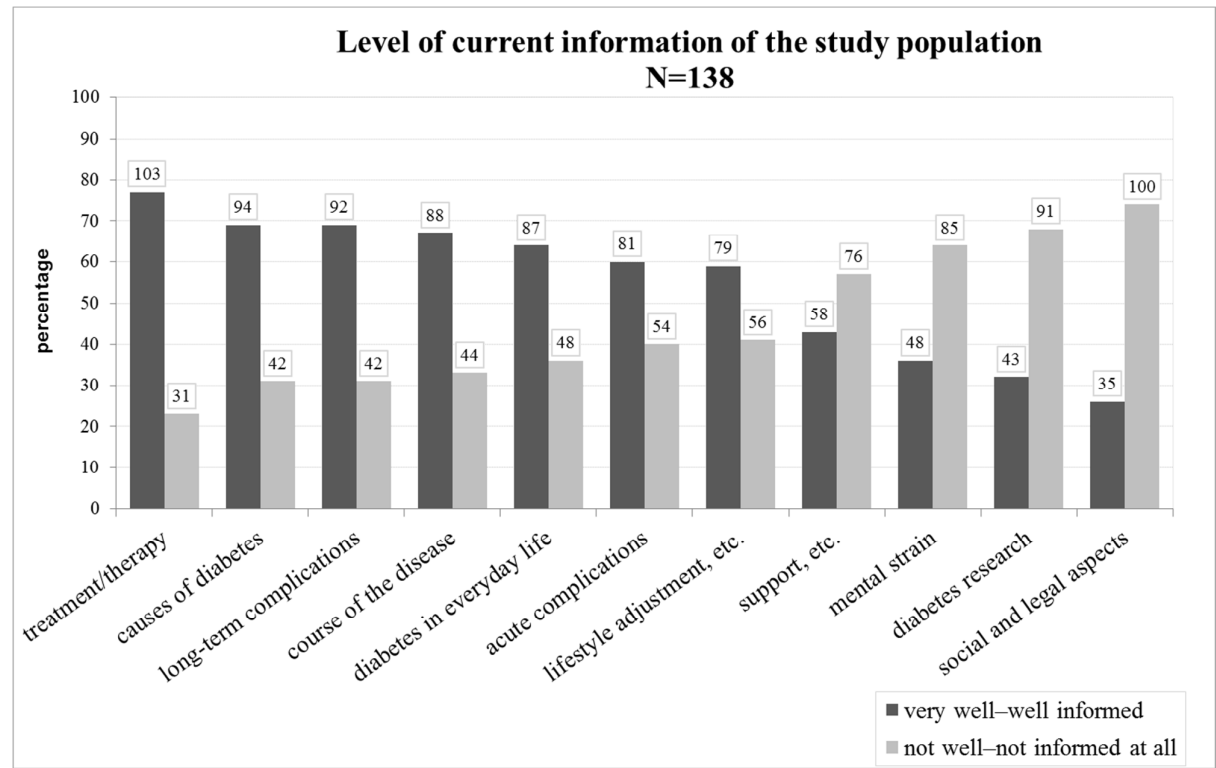
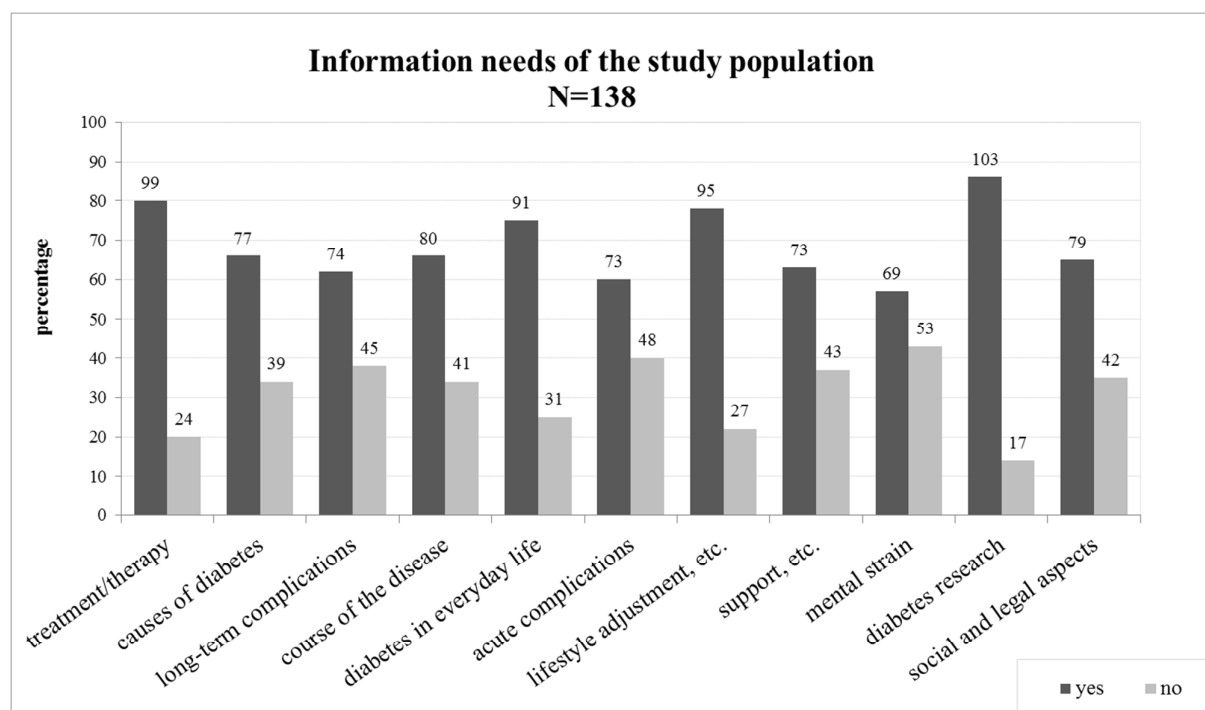


Figure 2



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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

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Complete List of Authors:	<p>Grobosch, Sandra; German Diabetes Center, Leibniz Center for Diabetes Research at Heinrich Heine University, Institute of Health Services Research and Health Economics; Heinrich Heine University Düsseldorf, Institute of Health Services Research and Health Economics, Centre for Health and Society, Faculty of Medicine</p> <p>Kuske, Silke; German Diabetes Center, Leibniz Center for Diabetes Research at Heinrich Heine University, Institute of Health Services Research and Health Economics; Heinrich Heine University Düsseldorf, Institute of Health Services Research and Health Economics, Centre for Health and Society, Faculty of Medicine</p> <p>Linnenkamp, Ute; German Diabetes Center, Leibniz Center for Diabetes Research at Heinrich Heine University, Institute of Health Services Research and Health Economics; German Center for Diabetes Research (DZD)</p> <p>Ernstmann, Nicole; University Hospital of Bonn, Center for Health Communication and Health Services Research, Department for Psychosomatic Medicine and Psychotherapy</p> <p>Stephan, Astrid; Heinrich Heine University Düsseldorf, Institute of Health Services Research and Health Economics, Centre for Health and Society, Faculty of Medicine</p> <p>Genz, Jutta; German Diabetes Center, Leibniz Center for Diabetes Research at Heinrich Heine University, Institute of Health Services Research and Health Economics</p> <p>Begun, Alexander; German Diabetes Center, Leibniz Center for Diabetes Research at Heinrich Heine University, Institute of Health Services Research and Health Economics; German Diabetes Center, Leibniz Center for Diabetes Research at Heinrich Heine University, Institute for Biometrics and Epidemiology</p> <p>Haastert, Burkhard; Heinrich Heine University Düsseldorf, Institute of Health Services Research and Health Economics, Centre for Health and Society, Faculty of Medicine; mediStatistica</p> <p>Szendroedi, Julia; Heinrich Heine University Düsseldorf, Division of Endocrinology and Diabetology, Faculty of Medicine; German Diabetes Center, Leibniz Center for Diabetes Research at Heinrich Heine University, Institute for Clinical Diabetology</p> <p>Müssig, Karsten; Heinrich Heine University Düsseldorf, Division of Endocrinology and Diabetology, Faculty of Medicine; German Diabetes Center, Leibniz Center for Diabetes Research at Heinrich Heine University, Institute for Clinical Diabetology</p> <p>Burkart, Volker; German Diabetes Center, Leibniz Center for Diabetes</p>

	Research at Heinrich Heine University, Institute for Clinical Diabetology; German Center for Diabetes Research (DZD) Roden, Michael; Heinrich Heine University Düsseldorf, Division of Endocrinology and Diabetology, Faculty of Medicine; German Diabetes Center, Leibniz Center for Diabetes Research at Heinrich Heine University, Institute for Clinical Diabetology Icks, Andrea; German Diabetes Center, Leibniz Center for Diabetes Research at Heinrich Heine University, Institute of Health Services Research and Health Economics; Heinrich Heine University Düsseldorf, Institute of Health Services Research and Health Economics, Centre for Health and Society, Faculty of Medicine
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

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1 1 What information needs do people with recently diagnosed diabetes mellitus have
2 2 and what are the associated factors? A cross-sectional study in Germany
3 3

4 4 Sandra Grobosch^{1,2,3*}, Silke Kuske^{1,2,*}, Ute Linnenkamp^{1,3}, Nicole Ernstmann⁴, Astrid Stephan²,
5 5 Jutta Genz¹, Alexander Begun^{1,5}, Burkhard Haastert^{2,6}, Julia Szendroedi^{7,8,3}, Karsten
6 6 Müssig^{7,8,3}, Volker Burkart^{8,3}, Michael Roden^{7,8,3,Z}, Andrea Icks^{1,2,3,Z} for the GDS Group**
7 7
8 8

9 9 Sandra Grobosch*, MSc.

10 10 1 Institute of Health Services Research and Health Economics, German Diabetes Center, Leibniz
11 11 Center for Diabetes Research at Heinrich Heine University, Düsseldorf, Germany

12 12 2 Institute of Health Services Research and Health Economics, Centre for Health and Society,
13 13 Faculty of Medicine, Heinrich Heine University Düsseldorf, Germany

14 14 3 German Center for Diabetes Research (DZD), München-Neuherberg, Germany
15 15

16 16 Silke Kuske*, PhD.

17 17 1 Institute of Health Services Research and Health Economics, German Diabetes Center, Leibniz
18 18 Center for Diabetes Research at Heinrich Heine University, Düsseldorf, Germany

19 19 2 Institute of Health Services Research and Health Economics, Centre for Health and Society,
20 20 Faculty of Medicine, Heinrich Heine University Düsseldorf, Germany
21 21

22 22 Ute Linnenkamp, MSc. MA.

23 23 1 Institute of Health Services Research and Health Economics, German Diabetes Center, Leibniz
24 24 Center for Diabetes Research at Heinrich Heine University, Düsseldorf, Germany

25 25 3 German Center for Diabetes Research (DZD), München-Neuherberg, Germany
26 26

27 27 Nicole Ernstmann, PhD.

28 28 4 Center for Health Communication and Health Services Research, Department for Psychosomatic
29 29 Medicine and Psychotherapy, University Hospital of Bonn, Bonn, Germany
30 30

31 31 Astrid Stephan, PhD.

32 32 2 Institute of Health Services Research and Health Economics, Centre for Health and Society,
33 33 Faculty of Medicine, Heinrich Heine University Düsseldorf, Germany
34 34

35 35 Jutta Genz, MSc.

36 36 1 Institute of Health Services Research and Health Economics, German Diabetes Center, Leibniz
37 37 Center for Diabetes Research at Heinrich Heine University, Düsseldorf, Germany
38 38

39 39 Alexander Begun, PhD.

40 40 1 Institute of Health Services Research and Health Economics, German Diabetes Center, Leibniz
41 41 Center for Diabetes Research at Heinrich Heine University, Düsseldorf, Germany

42 42 5 Institute for Biometrics and Epidemiology, German Diabetes Center, Leibniz Center for Diabetes
43 43 Research at Heinrich Heine University, Düsseldorf, Germany
44 44

45 45 Burkhard Haastert, PhD.

46 46 2 Institute of Health Services Research and Health Economics, Centre for Health and Society,
47 47 Faculty of Medicine, Heinrich Heine University Düsseldorf, Germany

48 48 6 mediStatistica, Neuenrade, Germany
49 49

50 50 Julia Szendroedi, MD.
51 51
52 52
53 53
54 54
55 55
56 56
57 57
58 58
59 59
60 60

1 51 7 Division of Endocrinology and Diabetology, Faculty of Medicine, Heinrich Heine University,
2 52 Düsseldorf, Germany
3
4 53 8 Institute for Clinical Diabetology, German Diabetes Center, Leibniz Center for Diabetes Research
5 54 at Heinrich Heine University, Düsseldorf, Germany
6 55 3 German Center for Diabetes Research (DZD), München-Neuherberg, Germany
7 56

8 57 Karsten Müssig, MD.

9
10 58 7 Division of Endocrinology and Diabetology, Faculty of Medicine, Heinrich Heine University,
11 59 Düsseldorf, Germany

12 60 8 Institute for Clinical Diabetology, German Diabetes Center, Leibniz Center for Diabetes Research
13 61 at Heinrich Heine University, Düsseldorf, Germany

14 62 3 German Center for Diabetes Research (DZD), München-Neuherberg, Germany
15 63

16 64 Volker Burkart, PhD.

17
18 65 8 Institute for Clinical Diabetology, German Diabetes Center, Leibniz Center for Diabetes Research
19 66 at Heinrich Heine University, Düsseldorf, Germany

20 67 3 German Center for Diabetes Research (DZD), München-Neuherberg, Germany
21 68

22 69 Michael Roden, MD., Z

23
24 70 7 Division of Endocrinology and Diabetology, Faculty of Medicine, Heinrich Heine University,
25 71 Düsseldorf, Germany

26 72 8 Institute for Clinical Diabetology, German Diabetes Center, Leibniz Center for Diabetes Research
27 73 at Heinrich Heine University, Düsseldorf, Germany

28 74 3 German Center for Diabetes Research (DZD), München-Neuherberg, Germany
29 75

30 76 Andrea Icks, MD. PhD. MBA., Z

31
32 77 1 Institute of Health Services Research and Health Economics, German Diabetes Center, Leibniz
33 78 Center for Diabetes Research at Heinrich Heine University, Düsseldorf, Germany

34 79 2 Institute of Health Services Research and Health Economics, Centre for Health and Society,
35 80 Faculty of Medicine, Heinrich Heine University Düsseldorf, Germany

36 81 3 German Center for Diabetes Research (DZD), München-Neuherberg, Germany
37 82

38
39 83 The GDS Group**

40 84 ** The GDS Group consists of M. Roden (speaker), H. Al-Hasani, A. E. Buyken, J. Eckel, G.
41 85 Geerling, C. Herder, A. Icks, J. Kotzka, O. Kuß, E. Lammert, D. Markgraf, K. Müssig, W.
42 86 Rathmann, J. Szendrödi, D. Ziegler and their co-workers.
43 87

44 88 * These authors contributed equally to this work (shared first authorship).

45 89 Z denotes shared senior authorship
46 90

47
48 91 Corresponding author:

49 92 Sandra Grobosch

50 93 Auf'm Hennekamp 65

51 94 40225 Düsseldorf, Germany

52 95 sandra.grobosch@ddz.uni-duesseldorf.de
53 96

54
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59

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10

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14 109
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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.

137 **Conclusion**

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

144 **Strengths and limitations of this study**

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

152 **Introduction**

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

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

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

173 **Methods**

174 **Study design and population**

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

1 177 prospective observational study initiated and coordinated by the German Diabetes Center (7). The
2
3
4 178 GDS aims to investigate the course of disease and the consequences of DM, and has been described
5
6 179 in detail elsewhere (7). Participants are people aged between 18 and 69 with recently diagnosed DM
7
8 180 with a duration of less than 12 months of known diabetes. Data assessment comprises standardised
9
10
11 181 questionnaires and interviews, detailed physical examinations and comprehensive metabolic
12
13 182 phenotyping.

15 183 The present study included 157 consecutive participants from the GDS between February 2014 and
16
17 184 May 2016. Nineteen participants were excluded due to missing variables, yielding 138 for the final
18
19
20 185 analysis.

24 187 **Ethical approval**

26
27 188 The GDS was approved by the ethics committee of Heinrich Heine University Düsseldorf (study
28
29 189 reference number 4508, previous reference number 2478). This study is performed according to the
30
31 190 Declaration of Helsinki and registered at Clinicaltrials.gov (Identifier: NCT01055093) (7).

36 192 **Patient and Public Involvement**

38 193 Patients and public were not involved in the present study. The questionnaire for measuring the
39
40
41 194 need for information was developed with the participation of people with DM in focus groups.

45 196 **Assessment of information needs**

47 197 Information needs were assessed using a questionnaire developed and evaluated by Chernyak *et al.*
48
49
50 198 (8). The German language version has been previously applied to a clinic-based population of
51
52 199 people with DM (8). The questionnaire is based on a mixed-methods design, namely a partially
53
54 200 mixed concurrent equal-status design (9). Both quantitative and qualitative data were assessed
55
56
57 201 without prioritising either of the methods.

1 202 It includes 11 topics of information needs (8): ‘causes of diabetes’, ‘course of the disease’,
2
3
4 203 ‘treatment/therapy’, ‘acute complications’, ‘late complications’, ‘diabetes in everyday life’, ‘mental
5
6 204 strain’, ‘lifestyle adjustment, health promotion and prevention’, ‘support, helplines and information
7
8 205 sources’, ‘social and legal aspects’ and ‘diabetes research’. Patients are able to mark whether
9
10
11 206 information is currently needed (no=0 / yes=1) for each topic and prioritise a number of the main
12
13 207 information needs. Furthermore, patients assess their current level of information for each topic
14
15 208 (very well, well, not well, not informed at all). Additionally, they can add an individual unlisted
16
17 209 information need. A blank text field is provided per information need to specify selected needs:
18
19
20 210 ‘Please explain what particular interests you have about these topics’. At the end of the information
21
22 211 needs questionnaire, the participants have the opportunity to reply to the question ‘What do you
23
24 212 consider to be particularly important with regard to information on diabetes?’ in a blank text field.
25
26
27 213

29 214 **Variables**

31 215 *Outcome: category of information need*

33
34 216 Three categories of information needs were defined for the purposes of the present study. The first
35
36 217 was the desire for information (no=0 / yes=1) on diabetes research. The second category focussed
37
38 218 on topics related to clinical factors of DM including a need for information on the causes of
39
40 219 diabetes, course of the disease, acute complications, long-term complications and mental strain. The
41
42
43 220 needs identified in the third category focussed on the management and handling of DM including
44
45 221 management-related topics, treatment/therapy, diabetes in everyday life, lifestyle adjustment, health
46
47 222 promotion and prevention, support, helplines and information sources, and social and legal aspects.
48
49
50 223 Within the second and third categories, results were summed up and dichotomised into ‘low
51
52 224 information needs’ (ranging from 0 to 2) or ‘high information needs’ (ranging from 3 to 5).
53
54
55 225

57 226 *Factors associated with information needs*

1 227 The associated factors were taken from the data assessed in GDS as described above. The variables
2
3
4 228 were selected as follows: firstly, a set of variables was deduced empirically from the existing
5
6 229 literature for quantitative analysis (10–15). Studies showed that age (years), sex, education, type of
7
8 230 diabetes, mode of diabetes treatment and health status appear to have an impact on information
9
10
11 231 needs (10–15). Education was coded by ‘other graduation’ and ‘university degree’; the type of
12
13 232 diabetes was coded by ‘type 1’, ‘type 2’ and ‘other’; mode of diabetes treatment was coded by ‘no
14
15 233 antihyperglycemic medication’, ‘oral glucose-lowering drugs’ and ‘insulin’. Health status was
16
17
18 234 defined according to diabetes-related comorbidities (nephropathy, neuropathy, peripheral arterial
19
20 235 occlusive disease, myocardial infarction, stroke, transient ischemic attack).

21
22 236 Secondly, five explorative groups of thematically relevant variables in the context of diabetes were
23
24
25 237 developed on a theoretical basis: (i) socio-economic factors are associated with diabetes-related
26
27 238 information-seeking behaviour (16). Further socio-economic factors in addition to education, which
28
29 239 has already been included, were therefore included: employment coded by ‘no’ or ‘yes’; school
30
31 240 graduation defined as ‘other graduation’ and ‘graduation from high school’; and migration
32
33
34 241 background, denoted by place of birth other than Germany or nationality other than German.

35
36 242 (ii) Past diabetes experience is associated with information needs (4). It can therefore be assumed
37
38 243 that diabetes-related and health-related factors may have an impact on information needs. Hence,
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40
41 244 besides diabetes type and mode of diabetes treatment which have already been included, the
42
43 245 duration of DM (time since diagnosis until inclusion in the GDS), HbA_{1c} and number of overall
44
45 246 drugs were also included.

46
47 247 (iii) As some studies on information needs also report on participation preferences and on the
48
49
50 248 people’s knowledge (4), this variable was added. Self-reported participation preferences, and thus
51
52 249 the wish to be involved in medical decision-making, were measured by the Control Preference
53
54 250 Scale, coded by ‘passive role’, ‘collaborative role’ and ‘active role’ (17). The information needs
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56
57 251 questionnaire included questions about current level of information. The current level of
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1
2 252 information on diabetes research was coded by ‘high current level of information’ (very well or
3
4 253 well informed) and ‘low current level of information’ (not well or not informed at all). The other
5
6 254 two categories of information needs were summed up and dichotomised into ‘high current level of
7
8 255 information’ (ranging from 0 to 6) as well as ‘low current level of information’ (ranging from 7 to
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10
11 256 15).

12
13 257 (iv) The fourth group of variables refers to depression and health-related quality of life. People with
14
15 258 DM have a higher prevalence of depression and a lower health-related quality of life than people
16
17 259 without DM (18, 19). This may lead to a lower level of activity. Depression was measured using the
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19
20 260 Center for Epidemiological Studies Depression Scale, long German version (ADS-L) (20) and
21
22 261 Problem Areas in Diabetes (PAID) survey (21, 22). In accordance with the respective published
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24 262 evaluation methods, depression was coded according to ADS-L as ‘clinically relevant depression’
25
26
27 263 (cut-off score >22) and according to PAID as ‘severe diabetes-related distress’ (cut-off score \geq 40).
28
29 264 Health-related quality of life was measured using the 36-Item Short-Form Health Survey (SF-36)
30
31 265 (23, 24) and analysed according to the physical and mental summary scales. In addition, the 5-Item
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33 266 World Health Organization Well-Being Index (WHO-5) questionnaire was analysed and quality of
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35
36 267 life was coded as ‘low quality of life’ (ranging from 0 to 12) and ‘high quality of life’ (ranging from
37
38 268 13 to 25) (25).

39
40
41 269 (v) Several studies have found that ‘self-management’ and ‘lifestyle’ are the main contents of the
42
43 270 information needs of people with DM (4), and thus the present study sought to identify a possible
44
45 271 association. Self-management was operationalised using three questions to be answered with yes or
46
47 272 no: ‘Do you have a health pass for diabetes?’, ‘Do you perform glucose self-monitoring?’ and
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49
50 273 ‘Have you ever participated in an education programme for people with diabetes?’. Variables that
51
52 274 provide statements on the participants’ lifestyles were included: body-mass index (BMI), smoking
53
54 275 behaviour and leisure time activity. BMI was categorised in accordance with the World Health
55
56
57 276 Organization definition (2005) (26), smoking behaviour was coded by ‘no answer’, ‘no’ and ‘yes’.

1 277 Leisure time activity was operationalised according to the Baecke index (27, 28) as a summary of
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3
4 278 the variables: ‘During leisure hours, I walk’, ‘During leisure hours, I ride a bike’ and ‘For how
5
6 279 many minutes a day do you walk or ride a bike going back and forth from work, school or
7
8 280 shopping?’.

13 282 **Quantitative analysis**

15 283 Firstly, descriptive analyses were performed (depending on the distribution of the variables by
16
17 284 frequencies, percentages, means \pm standard deviations).

20 285 To estimate associations between the information need categories as described above and associated
21
22 286 factors, multivariate logistic regression models were fitted, resulting in odds ratios (ORs) with 95%
23
24 287 confidence intervals (CI). Three groups of models were fitted, using the need for information (high
25
26 288 versus low) on diabetes research, clinical topics and management-related topics as a dependent
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28
29 289 binary variable.

31 290 The following steps were performed to select the final set of independent variables: We first
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33 291 included the six groups of variables described above fitting different models separately. We
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36 292 excluded variables due to many missing values, low impact in the regression analysis, low variation
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38 293 or high correlation to other covariables. Larger models were then fitted which included the
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41 294 independent variables of all six groups. After discussion of these models, fixed sets of independent
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43 295 variables including confounders were selected for the three main models. The final set of variables
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45 296 included: age, sex, education, type of diabetes (type 1 versus type 2), mode of diabetes treatment
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47 297 (antihyperglycemic medication yes versus no), diabetes-related comorbidity (binary), current level
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50 298 of information (high versus low), health-related quality of life (SF-36 physical and mental score)
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52 299 and BMI (>30 kg/m² versus ≤ 30 kg/m²).

54 300 With regard to the research-related information needs outcome, the corresponding model was only
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56
57 301 fitted in the subpopulation of subjects with type 2 diabetes, since all participants from the type 1
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1 302 subgroup were in need of information on diabetes research. The models for the clinical and
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4 303 management-related information needs outcomes were run both for the whole study population as
5
6 304 well as stratified for type 1 and type 2 diabetes. The mode of diabetes treatment was excluded for
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8 305 type 1 diabetes because only one participant in that subgroup did not use antihyperglycemic
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10 306 medication. SAS version 9.4 was used for all analyses.
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15 308 **Qualitative analysis**

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17 309 The qualitative content analysis was used for the free text entries and performed according to Elo
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20 310 and Kyngäs (2007) (29). A coding tree was developed by two coders, and one coder analysed all
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22 311 entries and the other reviewed the coding. According to the questionnaire, the theoretical and
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24 312 deductive pre-defined information need categories were first analysed deductively. A subsequent
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27 313 inductive analysis was performed to determine the subcategories. The inductive analysis entailed
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29 314 ‘open coding, creating categories and abstraction’. During that phase, the data was abstracted and
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31 315 described in order to define higher-order categories. The data was analysed several times to
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33
34 316 substantiate the codings of information needs.
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38 318 **Results**

39 40 41 319 *Participant characteristics*

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44 320 Approximately 60 % of the participants were male (Table 1). About half of them had a university
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46 321 degree, and three quarters were employed. One in ten had a migration background. More than 50 %
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48 322 had type 2 diabetes, and about one fifth were treated without antihyperglycemic medication.
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51 323 Participants took an average of three different drugs. Diabetes-related comorbidity was present in
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53 324 every sixth person.
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1 325 Most participants were not well informed or not informed at all about diabetes research (n=91)
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3
4 326 (Figure 1). Regarding clinical topics, the majority of participants reported that they were very well
5
6 327 or well informed about causes of diabetes (n=94), long-term complications (n=92), course of the
7
8 328 disease (n=88) and acute complications (n=81). Mental strain (n=85) was the only topic where not
9
10 329 well informed or not informed at all constituted the majority. The majority of participants reported
11
12
13 330 that they were very well or well informed about the following management-related topics:
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15 331 treatment/therapy (n=103), diabetes in everyday life (n=87), and lifestyle adjustment, health
16
17 332 promotion and prevention (n=79). The majority of participants stated that they were not well
18
19 333 informed or not informed at all regarding the topics support, helplines and information sources
20
21
22 334 (n=76), and social and legal aspects (n=100). There were more participants with a high current level
23
24 335 of information on clinical topics (n=62) than with a high current level of information on
25
26 336 management-related topics (n=47) (McNemar's test p=0.007).
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30

31 338 ***Quantitative results***

32 339 *Information needs*

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34 340 The majority of participants wished to gain information on all topics listed in the questionnaire
35
36 341 (Figure 2). Most of them (n=103) wished to have more information about diabetes research. Of the
37
38 342 clinical topics, participants showed the greatest need for information on the course of the disease
39
40
41 343 (n=80). The lowest need was stated for information on acute complications (n=73) and mental strain
42
43 344 (n=69). Management-related topics, e.g. treatment/therapy (n=99) and lifestyle adjustment, and
44
45 345 health promotion and prevention (n=95) were generally of more interest than clinical topics. The
46
47
48 346 lowest information need for management-related topics was found for support, helplines and
49
50
51 347 information sources (n=73). Four participants stated no information need.
52
53

54 348 The participants prioritised information about diabetes research (n=52) more than most topics
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56
57 349 allocated to the other two categories. A high information need was also reported for the clinical
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59

1 350 topics long-term complications (n=51) and causes of diabetes (n=40). The topics course of the
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4 351 disease (n=21) and mental strain (n=13), and especially the topic acute complications (n=5), were
5
6 352 rarely prioritised. The highest priority was reported for information about treatment/therapy as a
7
8 353 management-related topic. In the category management-related topics, high information needs were
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10
11 354 also reported for lifestyle adjustment, health promotion and prevention (n=51), and diabetes in
12
13 355 everyday life (n=42). The topics support, helplines and information sources (n=17), and social and
14
15 356 legal aspects (n=14) were rarely prioritised.

19 20 358 *Associated factors and concepts*

21
22 359 After excluding participants with missing values, the models were based on n=56 (diabetes
23
24 360 research, only type 2), n=93 (clinical topics) and n=93 (management-related topics) participants.

25
26
27 361 The current level of information, mode of diabetes treatment, diabetes-related comorbidity and
28
29 362 mental component summary score of the SF-36 are significantly associated with information needs:
30
31 363 participants who reported high current levels of information in clinical and management-related
32
33 364 topics were more likely to show a low information need both in clinical and management-related
34
35 365 topics (OR with 95 % CIs: 0.33 (0.13–0.86) and 0.28 (0.09–0.89)). The other factors were not
36
37 366 significantly associated with information needs; however, low statistical power should be
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41 367 considered in the interpretation of the non-significant results.

42
43 368 Subgroup analyses for patients with type 1 and type 2 diabetes showed that the current level of
44
45 369 information in clinical and management-related topics is significantly associated with information
46
47 370 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
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49
50 371 1 diabetes, higher mental component summary score of the SF-36 is associated with low
51
52 372 information needs concerning management-related topics (0.87 (0.76–0.995)). Participants with
53
54 373 type 2 diabetes treated with antihyperglycemic medication were more likely to have information
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56
57 374 needs regarding diabetes research compared to those without antihyperglycemic medication (6.98
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1 375 (1.38–35.22)). Existing comorbidities in people with type 2 diabetes were associated with low
2
3
4 376 information needs regarding diabetes research (0.04 (0.01–0.38)).
5

6 377 7 8 378 *Qualitative results* 9

10 379 Qualitative analysis showed that participants who sought information about topics in the category
11
12 380 diabetes research specifically expressed a need for information on study participation and results,
13
14 381 scientific developments (especially for cures, treatment (e.g. artificial pancreas)), and technical
15
16 382 devices (e.g. blood glucose measurement).
17

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20 383 Specific information needs that were stated for clinical topics, such as causes of diabetes, were:
21
22 384 causes of latent autoimmune diabetes in adults and people with type 1 diabetes in older age.
23

24 385 Participants wanted to know more about the course of the disease, especially a description of the
25
26 386 disease process and positive influences on the course of the disease. Wishes for information about
27
28 387 acute complications were not explained in more detail. As far as long-term complications are
29
30 388 concerned, participants expressed specific needs for information regarding the conditions under
31
32 389 which these long-term complications occur, and how symptoms can be prevented and recognised.
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34
35 390 Needs for information regarding mental strain included information on the impact on daily life,
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37 391 stress management and fear of hypoglycaemia.
38

39
40 392 Participants who were interested in the management-related topics category expressed specific
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42 393 information needs about treatment/therapy, in particular information on existing and new treatment
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44 394 options (e.g. continuous glucose monitoring, insulin pump therapy) and information about
45
46 395 simplified therapy, especially with less measuring and fewer insulin syringes. Specific needs in
47
48 396 diabetes in everyday life were: coping strategies in certain situations including tips for
49
50 397 simplification (e.g. holidays, work), diabetes management (e.g. time management, calculating
51
52 398 insulin or bread units) and interaction with people with DM. Information needs in the lifestyle
53
54 399 adjustment, health promotion and prevention category included information about sports and
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1 400 nutrition, tips and strategies for handling diabetes better, and possibilities to share experiences (e.g.
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3
4 401 health insurance, weight-loss clinic). In the support, helplines and information sources category,
5
6 402 participants expressed interest in an overview of existing support offers and education programs.
7
8 403 Participants who prioritised social and legal aspects wanted information about diabetes as a
9
10 404 disability and job-related information (e.g. terminating employment).
11
12
13 405 The results of the last open question identified a preference for information to be provided
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15 406 personally, in brochure and video form, or at specific information events. Patients expressed a
16
17 407 preference for information to be provided at all times especially recently after diagnosis and when
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19
20 408 new insights are gained, and for it to be comprehensive, transparent, neutral and of high quality.
21
22 409 Furthermore, participants expressed a wish for information to be adapted to their level of
23
24 410 knowledge.
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27 411
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29 412 *Synthesis of quantitative and qualitative results*

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31 413 The greatest level of interest was shown in the two categories diabetes research and management-
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33 414 related topics, particularly the topic treatment/therapy in the latter. Where diabetes research is
34
35 415 concerned, participants requested more information on new treatments and technical devices. In
36
37
38 416 both topics, there was a strong desire for information about new insights to simplify treatment.
39
40
41 417 Simplification and disease management are core qualitative aspects that appear to be relevant to
42
43 418 coping strategies in daily live. Individual characteristics such as existing knowledge appear to be
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45 419 particularly relevant to information needs and information provision. It can also be noted that
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47 420 participants requested information to be adapted to their level of knowledge.
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52 422 **Discussion**

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1 423 Participants with recently diagnosed DM have a high information need in all the topics concerning
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4 424 diabetes that were assessed with the information needs questionnaire. They express a particular
5
6 425 need for diabetes research and prefer more management-related topics than clinical topics.
7

8 426 Information needs concerning DM seem to be associated with current level of information, mode of
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10
11 427 diabetes treatment, diabetes-related comorbidity, and mental component summary score of the SF-
12
13 428 36.

15 429 The highest information need concerned diabetes research. This may be due to the fact that
16
17
18 430 participants in the GDS are more interested in research questions than people with DM who do not
19
20 431 participate in a research study (7, 30). The qualitative results indicate that participants wish
21
22 432 information to be up-to-date with the latest scientific findings. Another aim could be to verify
23
24 433 information provided by their physician (31). Other studies have also identified an interest in
25
26
27 434 information on recent scientific development (4).

29 435 In general, participants requested more information on management-related topics than on clinical
30
31 436 topics. The qualitative data clearly shows that the explanation of clinical topics frequently includes
32
33
34 437 management-related information. For example, participants stated that they would like to receive
35
36 438 more information on stress management. Resource-oriented provision of information is therefore
37
38 439 more likely to meet the needs of people with recently diagnosed diabetes. It can be assumed that
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40
41 440 this is related to the stage at which the recent diagnosis of diabetes was made and a presumably
42
43 441 better health status. A high need for information about treatment/therapy has also been identified by
44
45 442 other studies (5, 12, 14, 31–34).

47 443 The analysis of the two categories clinical topics and management-related topics showed that a low
48
49
50 444 current level of information is associated with a higher need for information. However, despite
51
52 445 being currently well informed, participants still required information on treatment/therapy. An
53
54 446 explanation could be: although people feel well informed, they do not have the specific information
55
56
57 447 which helps them to achieve their personal goal (for instance the simplification of everyday life).

1 448 The qualitative data shows that a number of participants would like more detailed information that
2
3
4 449 is adapted to their level of knowledge. In contrast, information on mental strain was rarely
5
6 450 prioritised, although a low current level of information was reported. St. Jean (2016) posited that a
7
8 451 lack of information sources or unconscious information could account for why relevant
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10
11 452 information cannot be obtained (31). The low information need concerning mental strain may also
12
13 453 be explained by the fact that the recently diagnosed participants do not experience mental strain.

14
15 454 In people with type 2 diabetes, antihyperglycemic medication appears to be associated with a
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17
18 455 greater need for information on diabetes research. This finding confirms a focus group analysis by
19
20 456 Lamberts et al. (2010), which showed a greater need for drug-related information in people who
21
22 457 have recently started treatment with oral glucose-lowering drugs (14).

23
24 458 Surprisingly, diabetes-related comorbidity in people with type 2 diabetes was associated with a
25
26
27 459 lower need for information for diabetes research. No other study reported this association.

28
29 460 Adjustments were made for the current level of information, but it cannot be ruled out that people
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31 461 with diabetes-related comorbidities are already well informed.

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33
34 462 In people with type 1 diabetes, higher mental component summary score of the SF-36 was
35
36 463 associated with lower information needs in management-related topics. The health-related quality of
37
38 464 life of people with type 1 diabetes is often reduced because of diabetes-related factors, for example
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40 465 fear of hypoglycaemia (also reported as an information need in the qualitative results) (35). In this
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42
43 466 study, people with higher mental component summary score of the SF-36 may feel that they do not
44
45 467 need any further information to manage their situation. Other studies show that optimistic feelings
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48 468 and support in diabetes experience were associated with different information needs in people with
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50 469 DM (4). No associations were found between information needs and sex, age, type of diabetes or
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52 470 further variables, possibly due to an insufficient statistical power to detect further significant
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54 471 associations.

1 472 Regarding the clinical implications of this study, results may contribute to an adjustment of the
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4 473 design of communication strategies and education programmes at an early stage of the disease.
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6 474 Some people with DM felt that they received enough information about diabetes and therefore did
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8 475 not attend self-management education programmes (36). An individual and patient-centred
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11 476 approach to building programs can increase participation.
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13 477 14 15 478 ***Limitations and strengths***

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17 479 The present observational study was not designed as a population-based study and therefore does
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20 480 not claim to represent the entire German diabetes population. Rather, it seeks to reveal predictors
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22 481 associated with later outcomes (e.g. diabetes-associated cardiovascular complications) in specific
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24 482 subgroups and to unravel underlying mechanisms (37). Compared with population-based
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27 483 representative samples, our cohort included more male and younger participants as well as more
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29 484 highly educated participants. Nevertheless, anthropometric data, such as BMI, was comparable to
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31 485 other German or European cohorts (37). However, the selection may introduce bias because the
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34 486 patients who participated in the GDS were potentially more motivated, which could suggest a
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36 487 higher current level of information.
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38 488 A limitation of the present study is its relatively low sample size and the large number of variables
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41 489 to be investigated as possible risk factors and confounders for information need. There is low
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43 490 statistical power to detect weaker associations. The results should therefore be interpreted with
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45 491 caution. In the ‘final models’, associations might be overweighted because of data-driven selection.
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48 492 Due to the low sample size, it was not possible to separate the data into two sets of training and test
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50 493 data for model building and validation of the final model. Furthermore, no adjustment for multiple
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52 494 testing was performed.
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54 495 The strengths of the present study are the possibility to analyse information needs in people with
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57 496 recently diagnosed diabetes, a relevant patient group for the provision of suitable information. It is
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1 497 noted that information needs may rise with the progression of the disease (31). The longitudinal
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4 498 design of GDS will allow a prospective analysis of the patients in this study. Another strength is: a
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6 499 large number of variables and their association with information needs could be analysed.
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10 501 **Conclusion**

12 502 In people with recently diagnosed diabetes, there is currently a high information need for all topics
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15 503 concerning diabetes, especially diabetes research and management-related topics, although study
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17 504 participants reported a relatively high level of being informed. Participants expressed a particular
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19 505 need for information regarding simplification of life with diabetes and for information adapted to
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22 506 their level of knowledge. Information needs differ between patient groups in that information needs
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24 507 are associated with the current level of information, mode of diabetes treatment, diabetes-related
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26 508 comorbidity and mental component summary score of the SF-36. This has to be considered when
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29 509 patients are provided with information about their disease. An open question is how information
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31 510 needs might change over the course of the disease. The prospective GDS provides the opportunity
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33 511 to analyse this question in the future.
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1 **Author's contribution**
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4 AI, MR, JS, KM, VB, SG, SK, UL, NE, AS, JG and GDS Group contributed to the concept, design, and drafting of
5
6 the present study. AI, SG, SK, AB, BH developed the design of the analysis. SG, AB, BH conducted formal
7
8 analysis. SK and AI supervised the analysis process. SG, SK and AI contributed to the writing of the manuscript;
9
10 all authors were involved in editing. All authors read and approved the final manuscript. The GDS Group and their
11
12 co-workers are responsible for the design and conduct of the GDS.
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17 **Data sharing statement**
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20 All available data can be obtained from the corresponding author.
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Table 1. Participants' characteristics

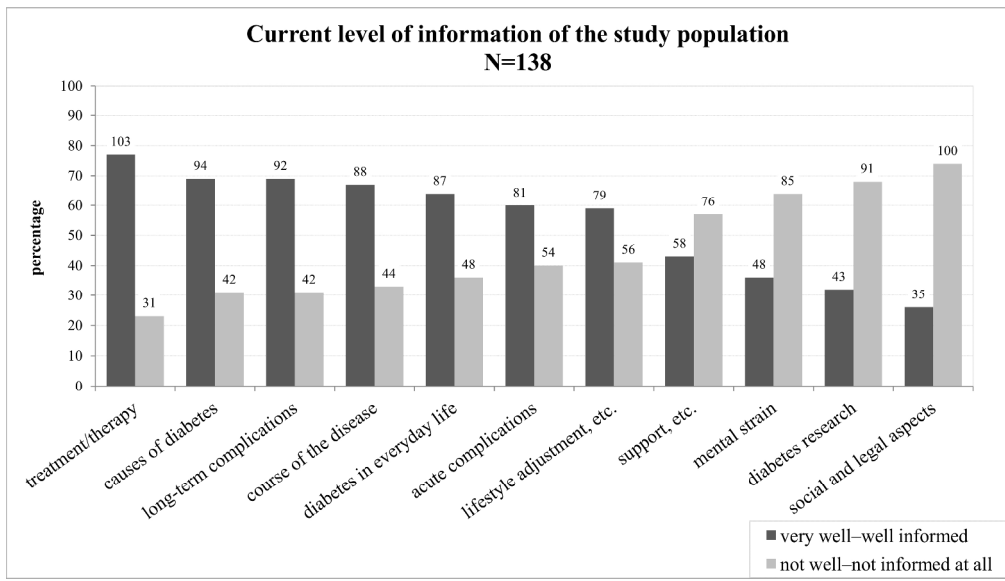
Characteristics	N (%)	mean (SD)
total number of participants	138	
age, n=138		46.3 (12.3)
sex, n=138	male female	88 (64) 50 (36)
university degree, n=135		64 (47)
employment, n=137		111(81)
migration background, n=136		18 (13)
type of diabetes, n=138	type 1 type 2 other	56 (41) 75 (54) 7 (5)
mode of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

1 *Figure 1. Current level of information of the study population on the diabetes-related topics (2–6 missings per variable)*
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4 *Figure 2. Information needs of the study population (15–22 missings per variable)*
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For peer review only

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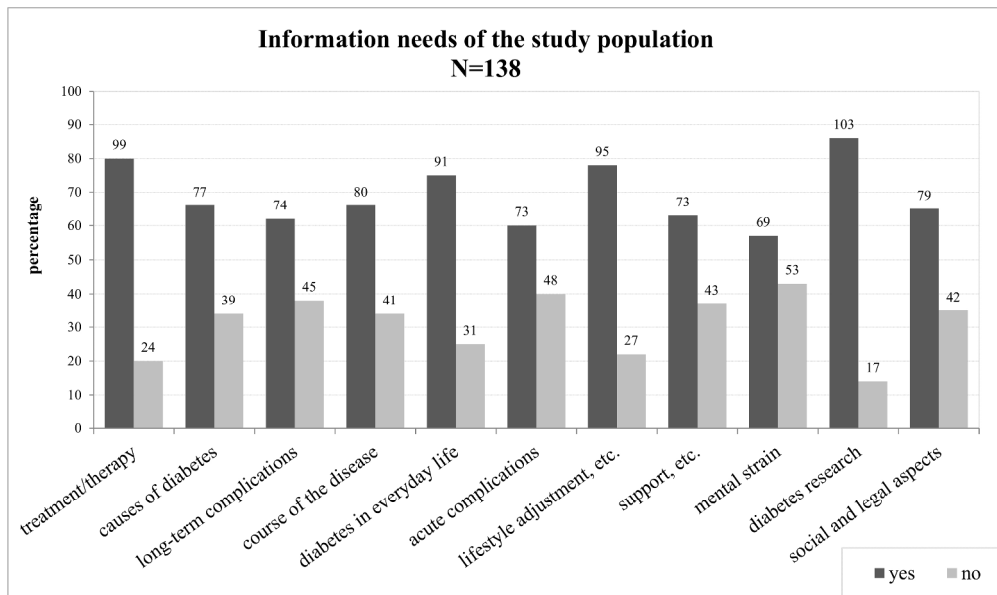


Current level of information of the study population on the diabetes-related topics (2–6 missings per variable)

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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:	<i>BMJ Open</i>
Manuscript ID	bmjopen-2017-017895.R2
Article Type:	Research
Date Submitted by the Author:	27-Jul-2018
Complete List of Authors:	<p>Grobosch, Sandra; German Diabetes Center, Leibniz Center for Diabetes Research at the Heinrich Heine University Düsseldorf, Institute for Health Services Research and Health Economics; Heinrich Heine University Düsseldorf, Institute for Health Services Research and Health Economics, Centre for Health and Society, Faculty of Medicine</p> <p>Kuske, Silke; German Diabetes Center, Leibniz Center for Diabetes Research at the Heinrich Heine University Düsseldorf, Institute for Health Services Research and Health Economics; Heinrich Heine University Düsseldorf, Institute for Health Services Research and Health Economics, Centre for Health and Society, Faculty of Medicine</p> <p>Linnenkamp, Ute; German Diabetes Center, Leibniz Center for Diabetes Research at the Heinrich Heine University Düsseldorf, Institute for Health Services Research and Health Economics; German Center for Diabetes Research (DZD)</p> <p>Ernstmann, Nicole; University Hospital of Bonn, Center for Health Communication and Health Services Research, Department for Psychosomatic Medicine and Psychotherapy</p> <p>Stephan, Astrid; Heinrich Heine University Düsseldorf, Institute for Health Services Research and Health Economics, Centre for Health and Society, Faculty of Medicine</p> <p>Genz, Jutta; German Diabetes Center, Leibniz Center for Diabetes Research at the Heinrich Heine University Düsseldorf, Institute for Health Services Research and Health Economics</p> <p>Begun, Alexander; German Diabetes Center, Leibniz Center for Diabetes Research at the Heinrich Heine University Düsseldorf, Institute for Health Services Research and Health Economics; German Diabetes Center, Leibniz Center for Diabetes Research at the Heinrich Heine University Düsseldorf, Institute for Biometrics and Epidemiology</p> <p>Haastert, Burkhard; Heinrich Heine University Düsseldorf, Institute for Health Services Research and Health Economics, Centre for Health and Society, Faculty of Medicine; mediStatistica</p> <p>Szendroedi, Julia; Heinrich Heine University Düsseldorf, Division of Endocrinology and Diabetology, Faculty of Medicine; German Diabetes Center, Leibniz Center for Diabetes Research at the Heinrich Heine University Düsseldorf, Institute for Clinical Diabetology</p> <p>Müssig, Karsten; Heinrich Heine University Düsseldorf, Division of Endocrinology and Diabetology, Faculty of Medicine; German Diabetes Center, Leibniz Center for Diabetes Research at the Heinrich Heine University Düsseldorf, Institute for Clinical Diabetology</p> <p>Burkart, Volker; German Diabetes Center, Leibniz Center for Diabetes</p>

	Research at the Heinrich Heine University Düsseldorf, Institute for Clinical Diabetology; German Center for Diabetes Research (DZD) Roden, Michael; Heinrich Heine University Düsseldorf, Division of Endocrinology and Diabetology, Faculty of Medicine; German Diabetes Center, Leibniz Center for Diabetes Research at the Heinrich Heine University Düsseldorf, Institute for Clinical Diabetology Icks, Andrea; German Diabetes Center, Leibniz Center for Diabetes Research at the Heinrich Heine University Düsseldorf, Institute for Health Services Research and Health Economics; Heinrich Heine University Düsseldorf, Institute for Health Services Research and Health Economics, Centre for Health and Society, Faculty of Medicine
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

SCHOLARONE™
Manuscripts

1 1 What information needs do people with recently diagnosed diabetes mellitus have
2 2 and what are the associated factors? A cross-sectional study in Germany
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4 4 Sandra Grobosch^{1,2,8*}, Silke Kuske^{1,2,*}, Ute Linnenkamp^{1,8}, Nicole Ernstmann³, Astrid Stephan²,
5 5 Jutta Genz¹, Alexander Begun^{1,4}, Burkhard Haastert^{2,5}, Julia Szendroedi^{6,7,8}, Karsten
6 6 Müssig^{6,7,8}, Volker Burkart^{7,8}, Michael Roden^{6,7,8,Z}, Andrea Icks^{1,2,8,Z} for the GDS Group**
7 7
8 8

9 9 Sandra Grobosch*, MSc.

10 10 1 Institute for Health Services Research and Health Economics, German Diabetes Center, Leibniz
11 11 Center for Diabetes Research at the Heinrich Heine University Düsseldorf, Düsseldorf, Germany

12 12 2 Institute for Health Services Research and Health Economics, Centre for Health and Society,
13 13 Faculty of Medicine, Heinrich Heine University Düsseldorf, Düsseldorf, Germany

14 14 8 German Center for Diabetes Research (DZD), München-Neuherberg, Germany
15 15

16 16 Silke Kuske*, PhD.

17 17 1 Institute for Health Services Research and Health Economics, German Diabetes Center, Leibniz
18 18 Center for Diabetes Research at the Heinrich Heine University Düsseldorf, Düsseldorf, Germany

19 19 2 Institute for Health Services Research and Health Economics, Centre for Health and Society,
20 20 Faculty of Medicine, Heinrich Heine University Düsseldorf, Düsseldorf, Germany
21 21

22 22 Ute Linnenkamp, MSc. MA.

23 23 1 Institute for Health Services Research and Health Economics, German Diabetes Center, Leibniz
24 24 Center for Diabetes Research at the Heinrich Heine University Düsseldorf, Düsseldorf, Germany

25 25 8 German Center for Diabetes Research (DZD), München-Neuherberg, Germany
26 26

27 27 Nicole Ernstmann, PhD.

28 28 3 Center for Health Communication and Health Services Research, Department for Psychosomatic
29 29 Medicine and Psychotherapy, University Hospital of Bonn, Bonn, Germany
30 30

31 31 Astrid Stephan, PhD.

32 32 2 Institute for Health Services Research and Health Economics, Centre for Health and Society,
33 33 Faculty of Medicine, Heinrich Heine University Düsseldorf, Düsseldorf, Germany
34 34

35 35 Jutta Genz, MSc.

36 36 1 Institute for Health Services Research and Health Economics, German Diabetes Center, Leibniz
37 37 Center for Diabetes Research at the Heinrich Heine University Düsseldorf, Düsseldorf, Germany
38 38

39 39 Alexander Begun, PhD.

40 40 1 Institute for Health Services Research and Health Economics, German Diabetes Center, Leibniz
41 41 Center for Diabetes Research at the Heinrich Heine University Düsseldorf, Düsseldorf, Germany

42 42 4 Institute for Biometrics and Epidemiology, German Diabetes Center, Leibniz Center for Diabetes
43 43 Research at the Heinrich Heine University Düsseldorf, Düsseldorf, Germany
44 44

45 45 Burkhard Haastert, PhD.

46 46 2 Institute for Health Services Research and Health Economics, Centre for Health and Society,
47 47 Faculty of Medicine, Heinrich Heine University Düsseldorf, Düsseldorf, Germany

48 48 5 mediStatistica, Neuenrade, Germany
49 49

50 50 Julia Szendroedi, MD.
51 51
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1 51 6 Division of Endocrinology and Diabetology, Faculty of Medicine, Heinrich Heine University
2 52 Düsseldorf, Düsseldorf, Germany
3
4 53 7 Institute for Clinical Diabetology, German Diabetes Center, Leibniz Center for Diabetes Research
5 54 at the Heinrich Heine University Düsseldorf, Düsseldorf, Germany
6 55 8 German Center for Diabetes Research (DZD), München-Neuherberg, Germany
7 56

8 57 Karsten Müssig, MD.

9 58 6 Division of Endocrinology and Diabetology, Faculty of Medicine, Heinrich Heine University
10 59 Düsseldorf, Düsseldorf, Germany
11
12 60 7 Institute for Clinical Diabetology, German Diabetes Center, Leibniz Center for Diabetes Research
13 61 at the Heinrich Heine University Düsseldorf, Düsseldorf, Germany
14 62 8 German Center for Diabetes Research (DZD), München-Neuherberg, Germany
15 63

16 64 Volker Burkart, PhD.

17 65 7 Institute for Clinical Diabetology, German Diabetes Center, Leibniz Center for Diabetes Research
18 66 at the Heinrich Heine University Düsseldorf, Düsseldorf, Germany
19 67 8 German Center for Diabetes Research (DZD), München-Neuherberg, Germany
20 68

21 69 Michael Roden, MD., Z

22 70 6 Division of Endocrinology and Diabetology, Faculty of Medicine, Heinrich Heine University
23 71 Düsseldorf, Düsseldorf, Germany
24 72 7 Institute for Clinical Diabetology, German Diabetes Center, Leibniz Center for Diabetes Research
25 73 at the Heinrich Heine University Düsseldorf, Düsseldorf, Germany
26 74 8 German Center for Diabetes Research (DZD), München-Neuherberg, Germany
27 75

28 76 Andrea Icks, MD. PhD. MBA., Z

29 77 1 Institute for Health Services Research and Health Economics, German Diabetes Center, Leibniz
30 78 Center for Diabetes Research at the Heinrich Heine University Düsseldorf, Düsseldorf, Germany
31 79 2 Institute for Health Services Research and Health Economics, Centre for Health and Society,
32 80 Faculty of Medicine, Heinrich Heine University Düsseldorf, Düsseldorf, Germany
33 81 8 German Center for Diabetes Research (DZD), München-Neuherberg, Germany
34 82

35 83 The GDS Group**

36 84 ** The GDS Group consists of M. Roden (speaker), H. Al-Hasani, A. E. Buyken, J. Eckel, G.
37 85 Geerling, C. Herder, A. Icks, J. Kotzka, O. Kuß, E. Lammert, D. Markgraf, K. Müssig, W.
38 86 Rathmann, J. Szendroedi, D. Ziegler and their co-workers.
39 87

40 88 * These authors contributed equally to this work (shared first authorship).

41 89 Z denotes shared senior authorship
42 90

43 91 Corresponding author:

44 92 Sandra Grobosch
45 93 Auf'm Hennekamp 65
46 94 40225 Düsseldorf, Germany
47 95 sandra.grobosch@ddz.uni-duesseldorf.de
48 96

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11 106 **Disclosure**

12 107
13 108 There are no conflicts of interest.
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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.

137 **Conclusion**

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

144 **Strengths and limitations of this study**

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

152 **Introduction**

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

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

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

173 **Methods**

174 **Study design and population**

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

1 177 prospective observational study initiated and coordinated by the German Diabetes Center (7). The
2
3
4 178 GDS aims to investigate the course of disease and the consequences of DM, and has been described
5
6 179 in detail elsewhere (7). Participants are people aged between 18 and 69 with recently diagnosed DM
7
8 180 with a duration of less than 12 months of known diabetes. Data assessment comprises standardised
9
10
11 181 questionnaires and interviews, detailed physical examinations and comprehensive metabolic
12
13 182 phenotyping.

15 183 The present study included 157 consecutive participants from the GDS between February 2014 and
16
17 184 May 2016. Nineteen participants were excluded due to missing variables, yielding 138 for the final
18
19
20 185 analysis.

24 187 **Ethical approval**

26
27 188 The GDS was approved by the ethics committee of Heinrich Heine University Düsseldorf (study
28
29 189 reference number 4508, previous reference number 2478). This study is performed according to the
30
31 190 Declaration of Helsinki and registered at Clinicaltrials.gov (Identifier: NCT01055093) (7).

36 192 **Patient and Public Involvement**

38 193 Patients and public were not involved in the present study. The questionnaire for measuring the
39
40
41 194 need for information was developed with the participation of people with DM in focus groups.

45 196 **Assessment of information needs**

47 197 Information needs were assessed using a questionnaire developed and evaluated by Chernyak *et al.*
48
49
50 198 (8) (Appendix 1). The German language version has been previously applied to a clinic-based
51
52 199 population of people with DM (8). The questionnaire is based on a mixed-methods design, namely a
53
54 200 partially mixed concurrent equal-status design (9). Both quantitative and qualitative data were
55
56
57 201 assessed without prioritising either of the methods.

1 202 It includes 11 topics of information needs (8): ‘causes of diabetes’, ‘course of the disease’,
2
3
4 203 ‘treatment/therapy’, ‘acute complications’, ‘late complications’, ‘diabetes in everyday life’, ‘mental
5
6 204 strain’, ‘lifestyle adjustment, health promotion and prevention’, ‘support, helplines and information
7
8 205 sources’, ‘social and legal aspects’ and ‘diabetes research’. Participants are able to mark whether
9
10
11 206 information is currently needed (no=0 / yes=1) and assess their current level of information for each
12
13 207 topic (very well, well, not well, not informed at all). Furthermore, participants can prioritise a
14
15 208 maximum of three topics for which they currently need information. A blank text field is provided
16
17 209 per information need to specify selected needs: ‘Please explain what particular interests you have
18
19
20 210 about these topics’. They can also add an individual unlisted information need in any question. At
21
22 211 the end of the information needs questionnaire, the participants have the opportunity to reply to the
23
24 212 question ‘What do you consider to be particularly important with regard to information on
25
26
27 213 diabetes?’ in a blank text field.
28
29 214

31 215 **Variables**

33 216 *Outcome: category of information need*

35
36 217 Three categories of information needs were defined for the purposes of the present study. The first
37
38 218 was the desire for information (no=0 / yes=1) on diabetes research. The second category focussed
39
40 219 on topics related to clinical factors of DM including a need for information on the causes of
41
42
43 220 diabetes, course of the disease, acute complications, long-term complications and mental strain. The
44
45 221 needs identified in the third category focussed on the management and handling of DM including
46
47 222 management-related topics, treatment/therapy, diabetes in everyday life, lifestyle adjustment, health
48
49
50 223 promotion and prevention, support, helplines and information sources, and social and legal aspects.
51
52 224 Within the second and third categories, results were summed up and dichotomised into ‘low
53
54 225 information needs’ (ranging from 0 to 2) or ‘high information needs’ (ranging from 3 to 5).
55
56
57 226

1 227 *Factors associated with information needs*

2
3
4 228 The associated factors were taken from the data assessed in GDS as described above. The variables
5
6 229 were selected as follows: firstly, a set of variables was deduced empirically from the existing
7
8 230 literature for quantitative analysis (10–15). Studies showed that age (years), sex, education, type of
9
10
11 231 diabetes, mode of diabetes treatment and health status appear to have an impact on information
12
13 232 needs (10–15). Education was coded by ‘other graduation’ and ‘university degree’; the type of
14
15 233 diabetes was coded by ‘type 1’, ‘type 2’ and ‘other’; mode of diabetes treatment was coded by ‘no
16
17
18 234 antihyperglycaemic medication’, ‘oral glucose-lowering drugs’ and ‘insulin’. Health status was
19
20 235 defined according to diabetes-related comorbidities (nephropathy, neuropathy, peripheral arterial
21
22 236 occlusive disease, myocardial infarction, stroke, transient ischemic attack).

23
24 237 Secondly, five explorative groups of thematically relevant variables in the context of diabetes were
25
26
27 238 developed on a theoretical basis: (i) socio-economic factors are associated with diabetes-related
28
29 239 information-seeking behaviour (16). Further socio-economic factors in addition to education, which
30
31 240 has already been included, were therefore included: employment coded by ‘no’ or ‘yes’; school
32
33
34 241 graduation defined as ‘other graduation’ and ‘graduation from high school’; and migration
35
36 242 background, denoted by place of birth other than Germany or nationality other than German.

37
38 243 (ii) Past diabetes experience is associated with information needs (4). It can therefore be assumed
39
40
41 244 that diabetes-related and health-related factors may have an impact on information needs. Hence,
42
43 245 besides diabetes type and mode of diabetes treatment which have already been included, the
44
45 246 duration of DM (time since diagnosis until inclusion in the GDS), HbA_{1c} and number of overall
46
47
48 247 drugs were also included.

49
50 248 (iii) As some studies on information needs also report on participation preferences and on the
51
52 249 people’s knowledge (4), this variable was added. Self-reported participation preferences, and thus
53
54 250 the wish to be involved in medical decision-making, were measured by the Control Preference
55
56
57 251 Scale, coded by ‘passive role’, ‘collaborative role’ and ‘active role’ (17). The information needs
58
59

1
2 252 questionnaire included questions about current level of information. The current level of
3
4 253 information on diabetes research was coded by 'high current level of information' (very well or
5
6 254 well informed) and 'low current level of information' (not well or not informed at all). The other
7
8 255 two categories of information needs were summed up and dichotomised into 'high current level of
9
10
11 256 information' (ranging from 0 to 6) as well as 'low current level of information' (ranging from 7 to
12
13 257 15).

14
15 258 (iv) The fourth group of variables refers to depression and health-related quality of life. People with
16
17 259 DM have a higher prevalence of depression and a lower health-related quality of life than people
18
19
20 260 without DM (18, 19). This may lead to a lower level of activity. Depression was measured using the
21
22 261 Center for Epidemiological Studies Depression Scale, long German version (ADS-L) (20) and
23
24 262 Problem Areas in Diabetes (PAID) survey (21, 22). In accordance with the respective published
25
26
27 263 evaluation methods, depression was coded according to ADS-L as 'clinically relevant depression'
28
29 264 (cut-off score >22) and according to PAID as 'severe diabetes-related distress' (cut-off score ≥ 40).
30
31 265 Health-related quality of life was measured using the 36-Item Short-Form Health Survey (SF-36)
32
33
34 266 (23, 24) and analysed according to the physical and mental summary scales. In addition, the 5-Item
35
36 267 World Health Organization Well-Being Index (WHO-5) questionnaire was analysed and quality of
37
38 268 life was coded as 'low quality of life' (ranging from 0 to 12) and 'high quality of life' (ranging from
39
40
41 269 13 to 25) (25).

42
43 270 (v) Several studies have found that 'self-management' and 'lifestyle' are the main contents of the
44
45 271 information needs of people with DM (4), and thus the present study sought to identify a possible
46
47 272 association. Self-management was operationalised using three questions to be answered with yes or
48
49
50 273 no: 'Do you have a health pass for diabetes?', 'Do you perform glucose self-monitoring?' and
51
52 274 'Have you ever participated in an education programme for people with diabetes?'. Variables that
53
54 275 provide statements on the participants' lifestyles were included: body-mass index (BMI), smoking
55
56
57 276 behaviour and leisure time activity. BMI was categorised in accordance with the World Health
58
59
60

1 277 Organization definition (2005) (26), smoking behaviour was coded by 'no answer', 'no' and 'yes'.
2
3
4 278 Leisure time activity was operationalised according to the Baecke index (27, 28) as a summary of
5
6 279 the variables: 'During leisure hours, I walk', 'During leisure hours, I ride a bike' and 'For how
7
8 280 many minutes a day do you walk or ride a bike going back and forth from work, school or
9
10
11 281 shopping?'.
12

13 282

15 283 **Quantitative analysis**

16
17 284 Firstly, descriptive summaries were obtained (depending on the distribution of the variables by
18
19
20 285 frequencies, percentages, means \pm standard deviations). Participants' current levels of information
21
22 286 were described in percentages. Comparisons between the different categories of information needs
23
24
25 287 were carried out using McNemar's test.

26
27 288 To estimate associations between the information need categories as described above and associated
28
29 289 factors, multivariate logistic regression models were fitted, resulting in odds ratios (ORs) with 95%
30
31 290 confidence intervals (CI) corresponding to 1 unit changes of the independent variable. Three groups
32
33
34 291 of models were fitted, using the categories of information needs (high versus low) as a dependent
35
36 292 binary variable.

37
38 293 The following steps were performed to select the final set of independent variables: we first
39
40
41 294 included the six groups of variables described above fitting different models separately. We
42
43 295 excluded variables due to many missing values, low impact in the regression analysis, low variation
44
45 296 or high correlation to other covariables. Larger models were then fitted which included the
46
47
48 297 independent variables of all six groups. After discussion of these models, fixed sets of independent
49
50 298 variables including confounders were selected for the three main models. The final set of variables
51
52 299 included: age, sex, education, mode of diabetes treatment (antihyperglycaemic medication yes
53
54 300 versus no), diabetes-related comorbidity (binary), current level of information (high versus low),
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1 301 health-related quality of life (mental and physical component summary score in the SF-36) and BMI
2
3
4 302 (≥ 30 kg/m² versus < 30 kg/m²).

5
6 303 With regard to the research-related information needs outcome, the corresponding model was only
7
8 304 fitted in the subpopulation of subjects with type 2 diabetes, since all participants from the type 1
9
10 305 subgroup were in need of information on diabetes research. The models for the clinical and
11
12 306 management-related information needs outcomes were run both for type 1 and type 2 diabetes. The
13
14 307 mode of diabetes treatment was excluded for type 1 diabetes because only one participant in that
15
16 308 subgroup did not use antihyperglycaemic medication. The data analysis for this paper was generated
17
18
19
20 309 using SAS software, Version 9.4 (SAS Institute Inc., Cary, NC).
21
22 310
23

24 311 **Qualitative analysis**

25
26 312 The qualitative content analysis was used for the free text entries and performed according to Elo
27
28 313 and Kyngäs (2007) (29). A coding tree was developed by two coders, and one coder analysed all
29
30 314 entries and the other reviewed the coding. According to the questionnaire, the theoretical and
31
32 315 deductive pre-defined information need categories were first analysed deductively. A subsequent
33
34 316 inductive analysis was performed to determine the subcategories. The inductive analysis entailed
35
36 317 ‘open coding, creating categories and abstraction’. During that phase, the data were abstracted and
37
38 318 described in order to define higher-order categories.
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42

43 319 44 320 **Results**

45 321 *Participant characteristics*

46
47 322 Approximately 60% of the participants were male (Table 1). About half of them had a university
48
49 323 degree, and three quarters were employed. One in eight had a migration background. More than
50
51 324 50% had type 2 diabetes, and about one fifth were treated without antihyperglycaemic medication.
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1 325 Participants took an average of three different drugs. Diabetes-related comorbidity was present in
2
3
4 326 every sixth person.
5

6 327 7 8 328 *Current level of information* 9

10 329 Most participants were not well informed or not informed at all about diabetes research (67.9%)
11
12 (Figure 1). Regarding clinical topics, the majority of participants reported that they were very well
13 330 or well informed about causes of diabetes (69.1%), long-term complications (68.7%), course of the
14
15 331 disease (66.7%) and acute complications (60%). Mental strain (63.9%) was the only topic where not
16
17 332 well informed or not informed at all constituted the majority. The majority of participants reported
18
19 333 that they were very well or well informed about the following management-related topics:
20
21 334 treatment/therapy (76.9%), diabetes in everyday life (64.4%), and lifestyle adjustment, health
22
23 335 promotion and prevention (58.5%). The majority of participants stated that they were not well
24
25 336 informed or not informed at all regarding the topics support, helplines and information sources
26
27 337 (56.7%), and social and legal aspects (74.1%). There were more participants with a high current
28
29 338 level of information on clinical topics (48.1%) than with a high current level of information on
30
31 339 management-related topics (35.6%) (McNemar's test $p=0.007$).
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33 340
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41 342 ***Quantitative results***

42 43 343 *Information needs* 44

45 344 When asked which topics they would like information on, the majority of participants stated a need
46
47 345 for information on all topics listed in the questionnaire (Figure 2). Most of them (85.8%) wished to
48
49 346 have more information about diabetes research. Of the clinical topics, participants showed the
50
51 347 greatest need for information on the course of the disease (66.1%). The lowest need was stated for
52
53 348 information on acute complications (60.3%) and mental strain (56.6%). Management-related topics,
54
55 349 e.g. treatment/therapy (80.5%) and lifestyle adjustment, and health promotion and prevention
56
57
58
59

1 350 (77.9%) were generally of more interest than clinical topics. The lowest information need for
2
3
4 351 management-related topics was found for support, helplines and information sources (62.9%). Four
5
6 352 participants stated no information need.
7

8 353 116 participants selected three prioritised topics, whilst some participants selected only two (n=10)
9
10
11 354 or one (n=5). Figure 3 shows the percentage with which each topic was selected as the priority from
12
13 355 all possible options (relative to all 131 participants with valid data). When asked to rank the three
14
15 356 most important topics (page one of the questionnaire, Appendix 1), participants prioritised
16
17 357 information about diabetes research (39.7%) more than most topics allocated to the other two
18
19 358 categories. A high information need was also reported for the clinical topics long-term
20
21 359 complications (38.9%) and causes of diabetes (29.8%). The topics course of the disease (15.3%)
22
23 360 and mental strain (9.9%), and especially the topic acute complications (3.8%), were rarely
24
25 361 prioritised. The highest priority was reported for information about treatment/therapy as a
26
27 362 management-related topic (48.1%). In the category management-related topics, high information
28
29 363 needs were also reported for lifestyle adjustment, health promotion and prevention (38.9%), and
30
31 364 diabetes in everyday life (32.1%). The topics support, helplines and information sources (13%), and
32
33 365 social and legal aspects (10.7%) were rarely prioritised.
34
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40 367 *Associated factors*

41
42
43 368 The multiple logistic regression models for participants with type 1 diabetes (Appendix 2a) showed
44
45 369 that the current level of information in clinical and management-related topics is significantly
46
47 370 associated with information needs (OR 0.17 (0.03–0.92) and 0.11 (0.02–0.75)). In people with type
48
49 371 1 diabetes, a higher mental component summary score in the SF-36 is significantly associated with
50
51 372 low information needs concerning management-related topics (OR 0.87 (0.76–0.995)).
52
53

54 373 Participants with type 2 diabetes (Appendix 2b) treated with antihyperglycaemic medication were
55
56 374 more likely to have information needs regarding diabetes research compared to those without
57
58
59

1 375 antihyperglycaemic medication (OR 6.98 (1.38–35.21)). Existing comorbidities in people with type
2 376 2 diabetes were associated with low information needs regarding diabetes research (OR 0.04 (0.01–
3
4 376 0.38)). However, low statistical power should be considered in the interpretation of the non-
5
6 377 0.38)). However, low statistical power should be considered in the interpretation of the non-
7
8 378 significant results.

9
10
11 379 If a Bonferroni adjustment for multiple testing for the number of independent variables were to be
12
13 380 considered, only the association of need for diabetes research and diabetes-related comorbidity
14
15 381 would remain significant in subjects with type 2 diabetes.

16 382 17 18 19 20 383 *Qualitative results*

21
22 384 Qualitative analysis showed that participants who sought information about topics in the category
23
24 385 diabetes research specifically expressed a need for information on study participation and results,
25
26 386 scientific developments (especially for cures, treatment (e.g. artificial pancreas)), and technical
27
28 387 devices (e.g. blood glucose measurement).

29
30
31 388 Specific information needs that were stated for clinical topics, such as causes of diabetes, were:
32
33 389 causes of latent autoimmune diabetes in adults and people with type 1 diabetes in older age.

34
35
36 390 Participants wanted to know more about the course of the disease, especially a description of the
37
38 391 disease process and positive influences on the course of the disease. Wishes for information about
39
40 392 acute complications were not explained in more detail. As far as long-term complications are
41
42 393 concerned, participants expressed specific needs for information regarding the conditions under
43
44 394 which these long-term complications occur, and how symptoms can be prevented and recognised.

45
46
47 395 Needs for information regarding mental strain included information on the impact on daily life,
48
49 396 stress management and fear of hypoglycaemia.

50
51
52 397 Participants who were interested in the management-related topics category expressed specific
53
54 398 information needs about treatment/therapy, in particular information on existing and new treatment
55
56 399 options (e.g. continuous glucose monitoring, insulin pump therapy) and information about
57
58
59

1 400 simplified therapy, especially with less measuring and fewer insulin syringes. Specific needs in
2
3
4 401 diabetes in everyday life were: coping strategies in certain situations including tips for
5
6 402 simplification (e.g. holidays, work), diabetes management (e.g. time management, calculating
7
8 403 insulin or bread units) and interaction with people with DM. Information needs in the lifestyle
9
10
11 404 adjustment, health promotion and prevention category included information about sports and
12
13 405 nutrition, tips and strategies for handling diabetes better, and possibilities to share experiences (e.g.
14
15 406 health insurance, weight-loss clinic). In the support, helplines and information sources category,
16
17
18 407 participants expressed interest in an overview of existing support offers and education programs.
19
20 408 Participants who prioritised social and legal aspects wanted information about diabetes as a
21
22 409 disability and job-related information (e.g. terminating employment).
23
24 410 The results of the last open question identified a preference for information to be provided
25
26
27 411 personally, in brochure and video form, or at specific information events. Patients expressed a
28
29 412 preference for information to be provided at all times especially recently after diagnosis and when
30
31 413 new insights are gained, and for it to be comprehensive, transparent, neutral and of high quality.
32
33
34 414 Furthermore, participants expressed a wish for information to be adapted to their level of
35
36 415 knowledge.
37

41 417 *Synthesis of quantitative and qualitative results*

42
43 418 The greatest level of interest was shown in the two categories diabetes research and management-
44
45 419 related topics, particularly the topic treatment/therapy in the latter. Where diabetes research is
46
47 420 concerned, participants requested more information on new treatments and technical devices. In
48
49
50 421 both topics, there was a strong desire for information about new insights to simplify treatment.
51
52 422 Simplification and disease management are core qualitative aspects that appear to be relevant to
53
54 423 coping strategies in daily live. Individual characteristics such as existing knowledge appear to be
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1
2 424 particularly relevant to information needs and information provision. It can also be noted that
3
4 425 participants requested information to be adapted to their level of knowledge.
5

8 427 **Discussion**

10
11 428 Participants with recently diagnosed DM have a high information need in all the topics concerning
12
13 429 diabetes that were assessed with the information needs questionnaire. They express a particular
14
15 430 need for diabetes research and prefer more management-related topics than clinical topics.
16
17
18 431 Information needs concerning DM seem to be associated with current level of information, mode of
19
20 432 diabetes treatment, diabetes-related comorbidity, and mental component summary score in the SF-
21
22 433 36.

24 434 The highest information need concerned diabetes research. This may be due to the fact that
25
26
27 435 participants in the GDS are more interested in research questions than people with DM who do not
28
29 436 participate in a research study (7, 30). The qualitative results indicate that participants wish
30
31
32 437 information to be up-to-date with the latest scientific findings. Another aim could be to verify
33
34 438 information provided by their physician (31). Other studies have also identified an interest in
35
36 439 information on recent scientific development (4).

38 440 In general, participants requested more information on management-related topics than on clinical
39
40
41 441 topics. The qualitative data clearly show that the explanation of clinical topics frequently includes
42
43 442 management-related information. For example, participants stated that they would like to receive
44
45 443 more information on stress management. Resource-oriented provision of information is therefore
46
47
48 444 more likely to meet the needs of people with recently diagnosed diabetes. It can be assumed that
49
50 445 this is related to the stage at which the recent diagnosis of diabetes was made and a presumably
51
52 446 better health status. A high need for information about treatment/therapy has also been identified by
53
54 447 other studies (5, 12, 14, 31–34).
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1 448 In people with type 1 diabetes, the analysis of the two categories clinical topics and management-
2
3 related topics showed that a low current level of information is associated with a higher need for
4 449
5 information. However, despite being currently well informed, participants still required information
6 450
7 on treatment/therapy. An explanation could be: although people feel well informed, they do not
8 451
9 have the specific information which helps them to achieve their personal goal (for instance the
10
11 452 simplification of everyday life). The qualitative data show that a number of participants would like
12
13 453 more detailed information that is adapted to their level of knowledge. In contrast, information on
14
15 454 mental strain was rarely prioritised, although a low current level of information was reported. St.
16
17
18 455 Jean (2016) posited that a lack of information sources or unconscious information could account
19
20 456 for why relevant information cannot be obtained (31). The low information need concerning mental
21
22 457 strain may also be explained by the fact that the recently diagnosed participants do not experience
23
24 458 mental strain.
25
26
27 459

28
29 460 A higher mental component summary score in the SF-36 was associated with lower information
30
31 461 needs in management-related topics in people with type 1 diabetes. The health-related quality of life
32
33 462 of people with type 1 diabetes is often reduced because of diabetes-related factors, for example fear
34
35 463 of hypoglycaemia (also reported as an information need in the qualitative results) (35). In this study,
36
37 464 people with a higher mental component summary score in the SF-36 may feel that they do not need
38
39 465 any further information to manage their situation. Other studies show that optimistic feelings and
40
41 466 support in diabetes experience were associated with different information needs in people with DM
42
43 467 (4).
44
45
46

47 468 In people with type 2 diabetes, antihyperglycaemic medication appears to be associated with a
48
49 greater need for information on diabetes research. This finding confirms a focus group analysis by
50 469
51 Lamberts et al. (2010), which showed a greater need for drug-related information in people who
52 470
53 have recently started treatment with oral glucose-lowering drugs (14).
54 471
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1 472 Surprisingly, diabetes-related comorbidity in people with type 2 diabetes was associated with a
2
3
4 473 lower need for information for diabetes research. No other study reported this association.
5
6 474 Adjustments were made for the current level of information, but it cannot be ruled out that people
7
8 475 with diabetes-related comorbidities are already well informed.

10
11 476 No associations were found between information needs and sex, age or further variables, possibly
12
13 477 due to an insufficient statistical power to detect further significant associations.

15 478 Regarding the clinical implications of this study, results may contribute to an adjustment of the
16
17
18 479 design of communication strategies and education programmes at an early stage of the disease.

20 480 Some people with DM felt that they received enough information about diabetes and therefore did
21
22 481 not attend self-management education programmes (36). An individual and patient-centred
23
24 482 approach to building programs can increase participation.

29 484 ***Limitations and strengths***

31 485 The present observational study was not designed as a population-based study and therefore does
32
33
34 486 not claim to represent the entire German diabetes population. Rather, it seeks to reveal predictors
35
36 487 associated with later outcomes (e.g. diabetes-associated cardiovascular complications) in specific
37
38 488 subgroups and to unravel underlying mechanisms (37). Compared with population-based
39
40
41 489 representative samples, our cohort included more male and younger participants as well as more
42
43 490 highly educated participants. Nevertheless, anthropometric data, such as BMI, were comparable to
44
45 491 other German or European cohorts (37). However, the selection may introduce bias because the
46
47
48 492 patients who participated in the GDS were potentially more motivated, which could suggest a
49
50 493 higher current level of information.

52 494 A limitation of the present study is its relatively low sample size and the large number of variables
53
54 495 to be investigated as possible risk factors and confounders for information need. There is low
55
56
57 496 statistical power to detect weaker associations. The results should therefore be interpreted with

1 497 caution. In the ‘final models’, associations might be overestimated because of data-driven selection.
2
3
4 498 However, due to the low sample size, it was not possible to separate the data into two sets of
5
6 499 training and test data for model building and validation of the final model. Furthermore, because of
7
8 500 multiple testing in many different regression models some significant results might have occurred
9
10
11 501 by chance with respect to alpha inflation. Reference is made to the effect of a possible Bonferroni
12
13 502 adjustment in the results section.

14
15 503 The strengths of the present study are the possibility to analyse information needs in people with
16
17 504 recently diagnosed diabetes, a relevant patient group for the provision of suitable information. It is
18
19
20 505 noted that information needs may rise with the progression of the disease (31). The longitudinal
21
22 506 design of GDS will allow a prospective analysis of the patients in this study. Another strength is: a
23
24 507 large number of variables and their association with information needs could be analysed.
25
26
27 508

28 **Conclusion**

29 509
30
31 510 In people with recently diagnosed diabetes, there is currently a high information need for all topics
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33 511 concerning diabetes, especially diabetes research and management-related topics, although study
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35 512 participants reported a relatively high level of being informed. Participants expressed a particular
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37
38 513 need for information regarding simplification of life with diabetes and for information adapted to
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40 514 their level of knowledge. Information needs differ between patient groups in that information needs
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42 515 are associated with the current level of information, mode of diabetes treatment, diabetes-related
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45 516 comorbidity and mental component summary score in the SF-36. This has to be considered when
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47 517 patients are provided with information about their disease. An open question is how information
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49 518 needs might change over the course of the disease. The prospective GDS provides the opportunity
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52 519 to analyse this question in the future.
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1 **Author's contribution**

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4 AI, MR, JS, KM, VB, SG, SK, UL, NE, AS and JG contributed to the concept, design, and drafting of the present
5
6 study. AI, SG, SK, AB, BH developed the design of the analysis. SG, AB, BH conducted formal analysis. SK and
7
8 AI supervised the analysis process. SG, SK and AI contributed to the writing of the manuscript; all authors were
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10 involved in editing. All authors read and approved the final manuscript.
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15 **Data sharing statement**

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17 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 female	88 (64) 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 type 2 other	56 (41) 75 (54) 7 (5)
mode of diabetes treatment, n=130	no antihyperglycaemic medication oral glucose-lowering drugs insulin oral glucose-lowering drugs and insulin	26 (20) 51 (39) 50 (38) 3 (2)
number of overall drugs, n=130		2.98 (1.91)
diabetes-related comorbidity, n=136		23 (17)

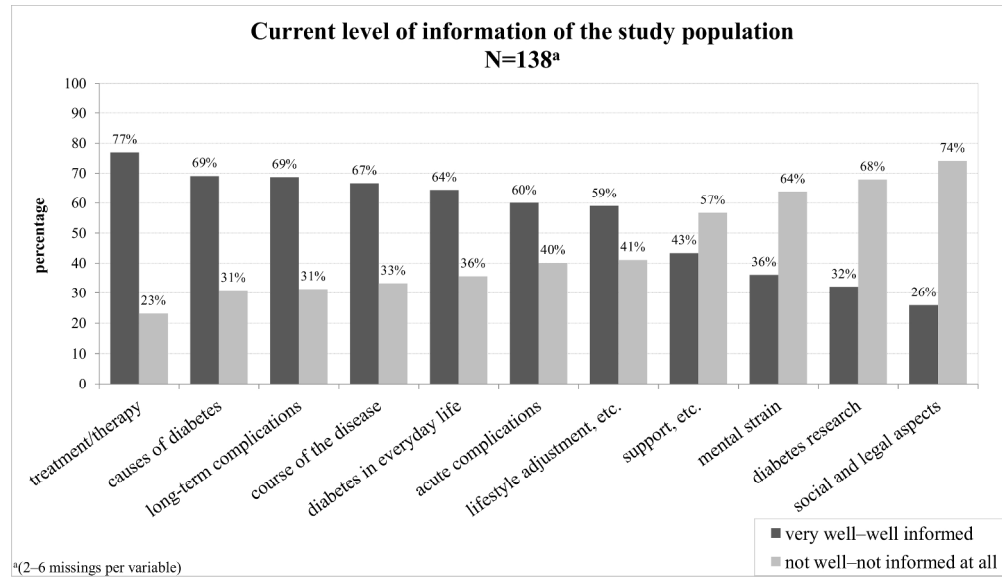
1 *Figure 1. Current level of information of the study population on the diabetes-related topics*

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4 *Figure 2. Information needs of the study population*

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7 *Figure 3. Topics mentioned as most important by participants*

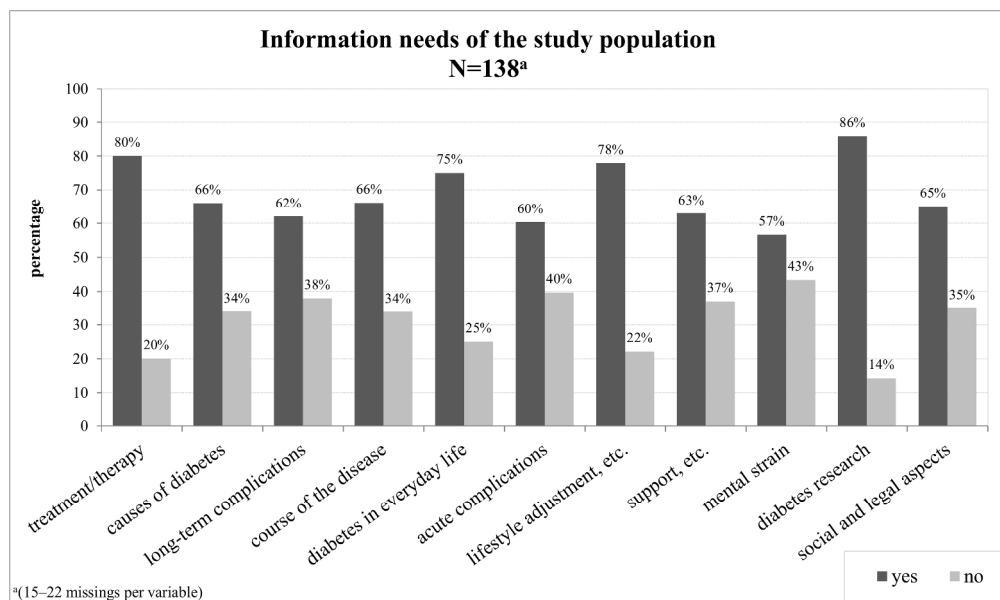
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26 Current level of information of the study population on the diabetes-related topics

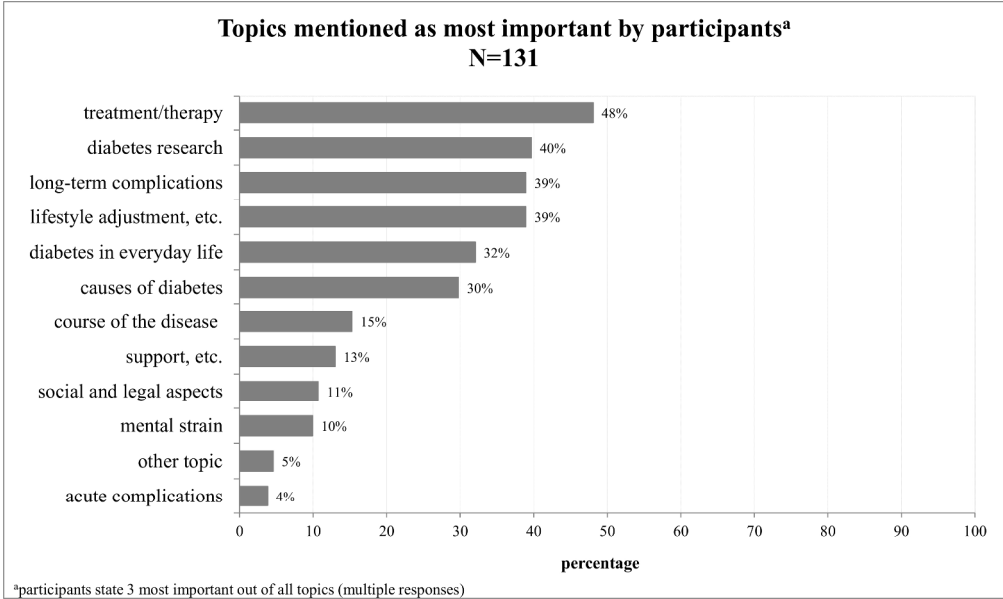
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Information needs of the study population

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Topics mentioned as most important by participants

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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
<input style="width: 60px; height: 30px;" type="text"/>	<hr/> <hr/>
<input style="width: 60px; height: 30px;" type="text"/>	<hr/> <hr/>
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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	<input type="checkbox"/> very well	<input type="checkbox"/> well	<input type="checkbox"/> not well	<input type="checkbox"/> not informed at all	<input type="checkbox"/> yes	<input type="checkbox"/> no
Course of the disease	<input type="checkbox"/> very well	<input type="checkbox"/> well	<input type="checkbox"/> not well	<input type="checkbox"/> not informed at all	<input type="checkbox"/> yes	<input type="checkbox"/> no
Treatment/therapy	<input type="checkbox"/> very well	<input type="checkbox"/> well	<input type="checkbox"/> not well	<input type="checkbox"/> not informed at all	<input type="checkbox"/> yes	<input type="checkbox"/> no
Acute complications	<input type="checkbox"/> very well	<input type="checkbox"/> well	<input type="checkbox"/> not well	<input type="checkbox"/> not informed at all	<input type="checkbox"/> yes	<input type="checkbox"/> no
Late complications	<input type="checkbox"/> very well	<input type="checkbox"/> well	<input type="checkbox"/> not well	<input type="checkbox"/> not informed at all	<input type="checkbox"/> yes	<input type="checkbox"/> no
Diabetes in everyday life	<input type="checkbox"/> very well	<input type="checkbox"/> well	<input type="checkbox"/> not well	<input type="checkbox"/> not informed at all	<input type="checkbox"/> yes	<input type="checkbox"/> no
Mental strain	<input type="checkbox"/> very well	<input type="checkbox"/> well	<input type="checkbox"/> not well	<input type="checkbox"/> not informed at all	<input type="checkbox"/> yes	<input type="checkbox"/> no
Lifestyle adjustment, health promotion and prevention	<input type="checkbox"/> very well	<input type="checkbox"/> well	<input type="checkbox"/> not well	<input type="checkbox"/> not informed at all	<input type="checkbox"/> yes	<input type="checkbox"/> no
Support, helplines and information sources	<input type="checkbox"/> very well	<input type="checkbox"/> well	<input type="checkbox"/> not well	<input type="checkbox"/> not informed at all	<input type="checkbox"/> yes	<input type="checkbox"/> no
Social and legal aspects	<input type="checkbox"/> very well	<input type="checkbox"/> well	<input type="checkbox"/> not well	<input type="checkbox"/> not informed at all	<input type="checkbox"/> yes	<input type="checkbox"/> no

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How well informed are you on the following topics?	Would you currently like information on the topic?
Scientific surveys and research on diabetes <input type="checkbox"/> very well <input type="checkbox"/> well <input type="checkbox"/> not well <input type="checkbox"/> not informed at all	<input type="checkbox"/> yes <input type="checkbox"/> no
Other topics not included in the list: _____	<input type="checkbox"/> yes <input type="checkbox"/> 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 diabetes¹

	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/m ²	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 \geq 30 kg/m ²	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