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# Structured diabetes self-management education and its association with perceived diabetes knowledge, information, and disease distress: Results of a nationwide population-based study

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ABSTRACT

*Objective:* To evaluate, how participation in structured diabetes self-management education (DSME) programs is associated with perceived level of knowledge about diabetes, information needs, information sources and disease distress.

*Methods:* We included 796 ever- and 277 never-DSME participants of the population-based survey "Disease knowledge and information needs - Diabetes mellitus (2017)" from Germany. Data on perceived level of diabetes knowledge (12 items), information needs (11 items), information sources (13 items) and disease distress (2 indices) were collected. Multiple logistic regression analyses were used to examine the association of DSME-participation with these outcomes.

*Results:* DSME-participants showed a higher level of diabetes knowledge compared to never-DSME participants, particularly in aspects concerning diabetes in general (odds ratio 2.53; 95% confidence intervals 1.48–4.33), treatment (2.41; 1.36–4.26), acute complications (1.91; 1.07–3.41) and diabetes in everyday life (1.83; 1.04–3.22). DSME-participants showed higher information needs regarding late complications (1.51; 1.04–2.18) and acute complications (1.71; 1.71–2.48) than DSME never participants. DSME-participants more frequently consulted diabetologists (5.54; 3.56–8.60) and diabetes care specialists (5.62; 3.61–8.75) as information sources. DSME participation was not associated with disease distress.

*Conclusion:* DSME is a valuable tool for improving individual knowledge about diabetes. However, DSME should focus more on psychosocial aspects to reduce the disease burden.

## 1. Introduction

Diabetes is a chronic disease that necessitates comprehensive self-care education and management to reduce macro- and microvascular complications and associated premature mortality. The success of diabetes care and glycaemic control depends largely on patients' self-management behaviour (SMB), e.g. individual behavioural changes, regular blood glucose testing or medication adherence [1,2].

In particular, individual knowledge about diabetes is an important aspect in this context, as it enables people with diabetes to actively self-manage their disease [3–5]. Although knowledge by itself is not sufficient to motivate behavioural change, previous research has shown that diabetes-specific knowledge is mediately associated with appropriate SMB and glycaemic control [6–10]. The ability to consult different sources of information and obtain information about diabetes treatment is therefore crucial to enable people with diabetes to manage the consequences of their disease [11,12].

While there is evidence that knowledge about diabetes is positively associated with SMB, disease distress and threatening perceptions of disease have been shown to adversely affect adherence to SMB [9,13,14]. Since diabetes-related distress reduces the perceived ability to cope with the disease [15], it is associated with suboptimal self-management [16] and precludes information behaviour [8]. People with diabetes, who hold threatening views about their illness, tend to adopt an adverse

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attitude and engage in less self-care practices [17]. Various studies have shown that diabetes distress is an important factor contributing to poor glycaemic control among people with diabetes [18,19].

Structured diabetes self-management education (DSME) programs are a critical element of care for people with diabetes that aims to influence diabetes knowledge and disease distress in a desirable way. DSME has consistently been demonstrated as an essential cornerstone in diabetes care, improving HbA1c levels [20], adherence in SMB [21,22] and psychosocial outcomes [23]. DSME seeks to provide participants with education about health-promoting behaviour, to empower active management of their disease in everyday life and to support informed decision-making [24]. International guidelines recommend participation in a DSME program at least once for each patient with diabetes [24,25]. In Germany, DSME is mainly offered in outpatient settings as group training with four to six participants or alternatively as individual counselling [26].

International studies show that DSME improves diabetes knowledge [27–33] and reduces disease distress [24,28,34,35]. However, since DSME is context-specific, these results cannot be readily generalized to the German population. Yet empirical findings based on nationwide data for Germany are still rare [4,36,37]. Given the scarcity of published German studies on this subject, the aim of the present study is to examine the association of DSME-participation with perceived level of information about diabetes, information needs, sources of information, and disease distress of people with diabetes.

## 2. Methods

### 2.1. Study design and population

The cross-sectional and nationwide survey "Disease knowledge and information needs -Diabetes mellitus (2017)" was designed by the Robert Koch Institute in cooperation with the Federal Centre for Health Education (BZgA) of Germany and the Institute of Medical Sociology and Rehabilitation Science of the Charité – Universitätsmedizin Berlin and conducted from September to November 2017. The data stemmed from two combined survey parts based on computer-assisted telephone interviews. The first part was based on a randomly selected sample of the German-speaking population aged 18 years and over. According to the dual-frame principle provided by the Working Group of German Market and Social Research Agencies (ADM) [38], 60% landline numbers and 40% mobile numbers were taken into account. This sample can be considered as representative of all private households in Germany that can potentially be reached by telephone. The response rate calculated according to AAPOR [39] criteria was 17.9%. Within this first part, 263 respondents reported a diabetes diagnosis. The second part applied a direct screening procedure for persons with diagnosed diabetes within a separate dual-frame sample, which comprised 1216 participants with a self-reported diabetes diagnosis. Details of participant sampling and questionnaire design are described elsewhere [36,37].

Among the 1479 people with diagnosed diabetes from both survey parts, 1396 participants reported having diabetes in the past 12 months or currently taking antidiabetic medication (excluding n = 40 participants with current or previous gestational diabetes and n = 43 participants who reported not having diabetes in the past 12 months and not currently taking diabetes medication). Of these, 1073 participants were included in the analysis as complete cases without missing data (excluding n = 90 participants with missing data for DSME or confounder variables and n = 233 participants with missing data for outcome variables).

The study was approved by the ethics committee of Berlin's Chamber of Physicians (reference number: Eth-23/17) and the Federal Commissioner for Data Protection and Freedom of Information of Germany. At the beginning of the telephone interview, all participants were informed about the goals and contents of the study, about privacy and data protection proceedings, and that their participation in the study was voluntary. All respondents gave their informed consent verbally.

### 2.2. Assessment of diabetes and DSME-participation

Participants were asked: "Has a doctor ever diagnosed you with diabetes?" Those who answered "yes" were asked in subsequent questions whether diabetes had persisted in the past 12 months and whether they were currently being treated with diabetes medication. Participants who answered affirmatively to any of these subsequent questions were classified as currently having diabetes. Participants with diabetes were then asked whether they had ever attended a DSME group training or an individual DSME training session. Interviewees who responded positively to at least one statement were classified as DSME participants.

### 2.3. Assessment of outcomes: perceived level of diabetes knowledge, information needs, information sources, and disease-related distress

Based on one newly developed item (using a 4-point scale adapted from the Perceived Kidney Knowledge Survey (PIKS [40]), participants were asked about their general knowledge regarding diabetes. Based on eleven additional items from the Information Needs in Diabetes Questionnaire (IND [41]), respondents were specifically asked how well they felt informed about diabetes with regard to different topics (using a 4-point Likert scale ranging from "very well-informed" to "not informed at all"). We use these twelve separate items as indicators for perceived level of information about diabetes in different subject areas. For the eleven items of the IND, participants could further indicate whether they currently need information (yes/no). We interpret these eleven separate items as indicators of information needs in different thematic areas related to diabetes. Based on 13 items taken from the DAWN2 study [42], respondents were asked to indicate their sources of information about diabetes (yes/no) by answering the question "Which of the following sources of information have you used so far to learn about diabetes?".

Two inventories were used to measure disease-related distress: The Problem Areas in Diabetes Scale (PAID-5) [18] and the Patient Health Questionnaire-2 (PHQ-2) [43]. PAID-5 is a summative index for measuring diabetes-related emotional distress, consisting of five Likert scaled items. The index has a sum value range of 0–20 points and has an internal consistency of Cronbach's $\alpha = 0.88$ within the present sample. A cut-off score of $\geq 8$ indicates a high diabetes-related emotional distress [18]. PHQ-2 is a two-question psychodiagnostic test for depressive symptoms. The index has a sum value ranging from 0 to 6 points. A cut-off score of $\geq 3$ indicates a high level of depressive symptoms and a high likelihood for depressive disorders [44]. The Spearman-Brown coefficient for the PHQ-2 within the present sample equals $\rho = 0.49$.

Psychometric properties of the aforementioned inventories within the present sample are described in detail elsewhere [45].

### 2.4. Sociodemographic and disease-related characteristics

A systematic review in Germany [4] not restricted to diabetes identified sex, age, education, disease duration and course of the disease as factors associated with information needs in various diseases. The following socio-demographic characteristics were therefore included as covariates in the statistical models to control for potential confounding: sex, age (years), educational level (classified according to CASMIN) [46], and occupational status (employed/not employed). Furthermore, we included the following disease-related characteristics as potential confounders: years since diabetes diagnosis, self-reported type of diabetes (type 1 diabetes/type 2 diabetes), insulin therapy (yes/no), therapy by oral antidiabetic drugs (OADs) (yes/no).

### 2.5. Statistical analysis

Proportions, means and standard deviations stratified according to

**Table 1**
Characteristics of the study population according to subgroups of participation in a structured patient education (DSME) program (n = 1073, complete-case analysis).

| | | DSME-never participants(n = 277) | | DSME-ever participants(n = 796) | | p |
|---|---|---|---|---|---|---|
| | | $n/n_{valid;}$M ± SD | % | $n/n_{valid;}$M ± SD | % | |
| n | | 277 | 24.2 | 796 | 75.8 | |
| **Sociodemographic characteristics** | | | | | | |
| Sex * | female | 145 | 54.9 | 375 | 48.7 | 0.153 |
| Age (years) | | 68.6 ± 14.8 (n = 277) | | 64.6 ± 12.7 (n = 796) | | **0.048** |
| Age (categorized) | 18–44 years | 3 | 5.7 | 18 | 6.3 | **0.042** |
| | 45–64 years | 64 | 28.7 | 269 | 42.5 | |
| | 65–79 years | 141 | 46.7 | 397 | 41.8 | |
| | 80 years or older | 69 | 19.0 | 112 | 9.3 | |
| Educational level | low | 80 | 47.8 | 203 | 43.1 | 0.405 |
| | middle | 121 | 40.0 | 351 | 42.3 | |
| | high | 76 | 12.1 | 242 | 14.5 | |
| Occupational status * † | employed | 43 | 20.9 | 182 | 30.0 | **0.054** |
| **Disease-related characteristics** | | | | | | |
| Years since diagnosis | | 11.0 ± 9.3 (n = 277) | | 15.8 ± 10.5 (n = 796) | | **< 0.01** |
| Type of diabetes * | type 2 diabetes | 264 | 94.9 | 661 | 79.8 | **< 0.01** |
| Current therapy * | insulin therapy | 74 | 31.9 | 440 | 55.8 | **< 0.01** |
| Current therapy * | oral antidiabetics | 209 | 74.6 | 479 | 59.1 | **< 0.01** |

This table shows unweighted absolute frequencies as well as weighted relative frequencies, weighted means and weighted standard deviations. The tests for significance (Student's t-tests respectively $\chi^2$-tests) take weighting factors into account. Symbols: * For dichotomous variables only one response category is shown. † The category "not employed" includes students and homemakers as well as retired or disabled respondents; Abbreviations: DSME – structured self-management education program for patients with diabetes mellitus, M ± SD – mean value ± standard deviation

**Table 2**
Association of DSME-participation with "very good" perceived level of information about different diabetes-related topics based on weighted logistic regression analyses (n = 1073; complete-case analysis; categories in order of predictive margins).

| Outcome | | | model 1 | | | model 2 | | | model 3 | | |
|---|---|---|---|---|---|---|---|---|---|---|---|
| | $\pi_{DSME}$ | $\pi_{never}$ | OR | 95%-C.I. | | OR | 95%-C.I. | | OR | 95%-C.I. | |
| General knowledge about diabetes | 27.4% | 10.9% | **3.10** | **[1.94;** | **4.96]** | **3.00** | **[1.77;** | **5.07]** | **2.53** | **[1.48;** | **4.33]** |
| Causes of diabetes | 21.5% | 12.5% | **1.91** | **[1.15;** | **3.17]** | **1.75** | **[1.04;** | **2.97]** | 1.57 | [0.93; | 2.68] |
| Treatment/therapy | 21.4% | 7.9% | **3.18** | **[1.85;** | **5.49]** | **2.91** | **[1.67;** | **5.06]** | **2.41** | **[1.36;** | **4.26]** |
| Late complications | 20.3% | 10.6% | **2.15** | **[1.24;** | **3.72]** | **1.91** | **[1.08;** | **3.35]** | 1.64 | [0.92; | 2.92] |
| Course of the disease | 20.1% | 10.7% | **2.10** | **[1.23;** | **3.56]** | **1.89** | **[1.10;** | **3.27]** | 1.67 | [0.96; | 2.90] |
| Acute complications | 16.9% | 7.6% | **2.46** | **[1.41;** | **4.29]** | **2.14** | **[1.21;** | **3.78]** | **1.91** | **[1.07;** | **3.41]** |
| Diabetes in everyday life | 15.9% | 7.4% | **2.36** | **[1.36;** | **4.08]** | **2.08** | **[1.20;** | **3.62]** | **1.83** | **[1.04;** | **3.22]** |
| Lifestyle adjustment, health promotion and prevention | 14.7% | 7.3% | **2.18** | **[1.20;** | **3.94]** | **1.93** | **[1.05;** | **3.54]** | 1.80 | [0.96; | 3.37] |
| Support, helplines and information sources | 11.3% | 5.5% | **2.20** | **[1.12;** | **4.29]** | **1.98** | **[1.00;** | **3.91]** | 1.69 | [0.84; | 3.39] |
| Mental strain | 11.0% | 4.6% | **2.55** | **[1.22;** | **5.30]** | **2.25** | **[1.07;** | **4.76]** | 1.93 | [0.91; | 4.08] |
| Social and legal aspects | 8.2% | 3.4% | **2.53** | **[1.05;** | **6.13]** | 2.34 | [0.87; | 6.30] | 1.81 | [0.71; | 4.61] |
| Scientific surveys and research on diabetes | 6.6% | 2.5% | 2.77 | [0.99; | 7.71] | 2.39 | [0.85; | 6.72] | 2.31 | [0.83; | 6.46] |

Notes: All outcomes originally used a 4-point Likert-scale but were dichotomized as "very good" vs. "good or worse"; model 1: zero-order association between DSME-participation and outcome; model 2: model 1 + adjustment for sociodemographic characteristics as described in Table 1; model 3: model 2 + adjustment for disease-related characteristics as described in Table 1; Abbreviations: DSME – structured self-management education program for patients with diabetes mellitus; $\pi_{never}$ – zero-order predictive margins among DSME-never participants; $\pi_{DSME}$ – zero-order predictive margins among DSME-ever participants; OR – odds ratio; CI – confidence interval; Significant effects ($p < 0.05$) are marked in bold and take weighting factors into account

**Table 3**
Association of DSME-participation with self-reported desire for information on diabetes-related topics based on weighted logistic regression analyses (n = 1073; complete-case analysis; categories in order of predictive margins).

| Outcome | | | model 1 | | | model 2 | | | model 3 | | |
|---|---|---|---|---|---|---|---|---|---|---|---|
| | $\pi_{DSME}$ | $\pi_{never}$ | OR | 95%-C.I. | | OR | 95%-C.I. | | OR | 95%-C.I. | |
| Scientific surveys and research on diabetes | 56.1% | 39.0% | **2.00** | **[1.42;** | **2.82]** | **1.78** | **[1.17;** | **2.71]** | **1.80** | **[1.18;** | **2.74]** |
| Treatment/therapy | 53.6% | 51.0% | 1.11 | [0.78; | 1.56] | 1.04 | [0.74; | 1.44] | 1.04 | [0.74; | 1.46] |
| Social and legal aspects | 51.2% | 42.2% | **1.44** | **[1.02;** | **2.03]** | 1.31 | [0.88; | 1.96] | 1.36 | [0.89; | 2.07] |
| Late complications | 50.9% | 41.1% | **1.49** | **[1.06;** | **2.10]** | **1.48** | **[1.04;** | **2.10]** | **1.51** | **[1.04;** | **2.18]** |
| Support, helplines and information sources | 50.4% | 42.1% | 1.40 | [0.99; | 1.97] | 1.37 | [0.94; | 1.99] | 1.43 | [0.96; | 2.14] |
| Acute complications | 46.6% | 36.2% | **1.54** | **[1.09;** | **2.18]** | **1.56** | **[1.09;** | **2.22]** | **1.71** | **[1.17;** | **2.48]** |
| Lifestyle adjustment, health promotion and prevention | 44.6% | 42.0% | 1.11 | [0.79; | 1.58] | 1.05 | [0.71; | 1.56] | 1.12 | [0.75; | 1.67] |
| Diabetes in everyday life | 41.4% | 41.1% | 1.01 | [0.71; | 1.43] | 0.99 | [0.69; | 1.43] | 1.03 | [0.71; | 1.49] |
| Course of the disease | 40.8% | 39.6% | 1.05 | [0.74; | 1.48] | 1.10 | [0.78; | 1.55] | 1.18 | [0.83; | 1.69] |
| Mental strain | 38.5% | 31.9% | 1.34 | [0.90; | 1.98] | 1.23 | [0.85; | 1.78] | 1.24 | [0.85; | 1.82] |
| Causes of diabetes | 35.9% | 39.4% | 0.86 | [0.60; | 1.25] | 0.92 | [0.61; | 1.37] | 0.94 | [0.62; | 1.43] |

Notes: All outcomes originally used dichotomous response categories ("desire for further information" vs. "no desire"); model 1: zero-order association between DSME-participation and outcome; model 2: model 1 + adjustment for sociodemographic characteristics as described in Table 1; model 3: model 2 + adjustment for disease-related characteristics as described in Table 1; Abbreviations: DSME – structured self-management education program for patients with diabetes mellitus; $\pi_{never}$ – zero-order predictive margins among DSME-never participants; $\pi_{DSME}$ – zero-order predictive margins among DSME-ever participants; OR – odds ratio; CI – confidence interval; Significant effects ($p < 0.05$) are marked in bold and take weighting factors into account

**Table 4**
Association of DSME-participation with sources of information used to learn about diabetes based on weighted logistic regression analyses (n = 1073; complete-case analysis; categories in order of predictive margins).

| Outcome | | | model 1 | | | model 2 | | | model 3 | | |
|---|---|---|---|---|---|---|---|---|---|---|---|
| | $\pi_{DSME}$ | $\pi_{never}$ | OR | 95%-C.I. | | OR | 95%-C.I. | | OR | 95%-C.I. | |
| General practitioner | 91.7% | 95.9% | 0.47 | [0.21; | 1.06] | 0.51 | [0.22; | 1.16] | 0.73 | [0.31; | 1.71] |
| Brochures, newspapers, books | 86.8% | 83.5% | 1.30 | [0.80; | 2.11] | 1.34 | [0.80; | 2.26] | 1.46 | [0.86; | 2.50] |
| Diabetologist | 72.0% | 25.6% | **7.47** | **[5.16;** | **10.82]** | **7.16** | **[4.73;** | **10.86]** | **5.54** | **[3.56;** | **8.60]** |
| Radio, TV, DVD | 59.8% | 52.7% | 1.34 | [0.94; | 1.90] | **1.55** | **[1.10;** | **2.18]** | **1.50** | **[1.05;** | **2.15]** |
| Diabetes Care and Education Specialist | 58.3% | 17.4% | **6.65** | **[3.94;** | **11.24]** | **6.47** | **[4.16;** | **10.06]** | **5.62** | **[3.61;** | **8.75]** |
| Websites | 40.7% | 25.4% | **2.02** | **[1.42;** | **2.88]** | **1.74** | **[1.16;** | **2.61]** | **1.92** | **[1.27;** | **2.91]** |
| Pharmacist | 32.8% | 22.9% | **1.64** | **[1.13;** | **2.40]** | **1.78** | **[1.21;** | **2.60]** | **1.62** | **[1.10;** | **2.40]** |
| Acquainted person with diabetes | 29.2% | 25.3% | 1.22 | [0.78; | 1.90] | 1.11 | [0.75; | 1.65] | 1.11 | [0.74; | 1.68] |
| Social networks and forums | 18.6% | 11.5% | **1.75** | **[1.09;** | **2.81]** | 1.45 | [0.86; | 2.45] | 1.50 | [0.90; | 2.52] |
| Other sources of information | 14.4% | 11.3% | 1.32 | [0.83; | 2.11] | 1.24 | [0.78; | 1.96] | 1.23 | [0.75; | 1.99] |
| Support group | 10.9% | 3.6% | **3.25** | **[1.56;** | **6.81]** | **3.07** | **[1.47;** | **6.43]** | **2.85** | **[1.37;** | **5.91]** |
| Diabetes Hotline, Physician Hotline | 10.4% | 15.5% | 0.63 | [0.35; | 1.16] | 0.63 | [0.32; | 1.25] | 0.56 | [0.30; | 1.05] |
| Alternative / naturopathic practitioner | 7.2% | 4.7% | 1.57 | [0.79; | 3.09] | 1.40 | [0.71; | 2.76] | 1.28 | [0.64; | 2.55] |

Notes: All outcomes originally used dichotomous response categories ("source of information used" vs. "not used"); model 1: zero-order association between DSME-participation and outcome; model 2: model 1 + adjustment for sociodemographic characteristics as described in Table 1; model 3: model 2 + adjustment for disease-related characteristics as described in Table 1; Abbreviations: DSME – structured self-management education program for patients with diabetes mellitus; $\pi_{never}$ – zero-order predictive margins among DSME-never participants; $\pi_{DSME}$ – zero-order predictive margins among DSME-ever participants; OR – odds ratio; CI – confidence interval

**Table 5**
Association of DSME-participation with depressive symptoms (PHQ-2) and diabetes-related emotional distress (PAID-5) based on weighted logistic regression analyses (n = 1073; complete-case analysis).

| Outcome | | | model 1 | | | model 2 | | | model 3 | | |
|---|---|---|---|---|---|---|---|---|---|---|---|
| | $\pi_{DSME}$ | $\pi_{never}$ | OR | 95%-C.I. | | OR | 95%-C.I. | | OR | 95%-C.I. | |
| High diabetes-related emotional distress(cut-off score of ≥ 8 on the PAID-5) | 15.4% | 13.4% | 1.18 | [0.60; | 2.31] | 1.03 | [0.59; | 1.80] | 0.73 | [0.40; | 1.33] |
| High level of depressive symptoms(cut-off score of ≥ 3 on the PHQ-2) | 16.9% | 17.9% | 0.93 | [0.60; | 1.46] | 0.93 | [0.57; | 1.49] | 0.89 | [0.55; | 1.44] |

Notes: Model 1: zero-order association between DSME-participation and outcome; model 2: model 1 + adjustment for sociodemographic characteristics as described in Table 1; model 3: model 2 + adjustment for disease-related characteristics as described in Table 1; Abbreviations: DSME – structured self-management education program for patients with diabetes mellitus; $\pi_{never}$ – zero-order predictive margins among DSME-never participants; $\pi_{DSME}$ – zero-order predictive margins among DSME-ever participants; OR – odds ratio; CI – confidence interval

**Table A.1**
Sensitivity analyses of association between DSME-participation and "very good" perceived level of information about different diabetes-related topics based on weighted logistic regression analyses (n = 1396; multiple imputation by chained equations).

| Outcome | | | model 1 | | | model 2 | | | model 3 | | |
|---|---|---|---|---|---|---|---|---|---|---|---|
| | $\pi_{DSME}$ | $\pi_{never}$ | OR | 95%-C.I. | | OR | 95%-C.I. | | OR | 95%-C.I. | |
| General knowledge about diabetes | 25.8% | 9.5% | **3.31** | **[2.19;** | **5.01]** | **3.19** | **[2.06;** | **4.95]** | **2.80** | **[1.78;** | **4.40]** |
| Causes of diabetes | 20.0% | 10.4% | **2.16** | **[1.39;** | **3.37]** | **1.98** | **[1.25;** | **3.13]** | **1.78** | **[1.12;** | **2.84]** |
| Treatment/therapy | 20.5% | 9.3% | **2.53** | **[1.61;** | **3.96]** | **2.30** | **[1.45;** | **3.66]** | **2.00** | **[1.25;** | **3.21]** |
| Late complications | 18.9% | 9.3% | **2.27** | **[1.39;** | **3.69]** | **2.00** | **[1.21;** | **3.31]** | **1.80** | **[1.08;** | **3.01]** |
| Course of the disease | 18.5% | 11.0% | **1.84** | **[1.18;** | **2.86]** | **1.66** | **[1.05;** | **2.61]** | 1.52 | [0.95; | 2.42] |
| Acute complications | 15.5% | 7.3% | **2.32** | **[1.41;** | **3.82]** | **2.01** | **[1.20;** | **3.35]** | **1.85** | **[1.10;** | **3.11]** |
| Diabetes in everyday life | 15.1% | 7.9% | **2.08** | **[1.29;** | **3.36]** | **1.84** | **[1.12;** | **3.02]** | **1.69** | **[1.02;** | **2.79]** |
| Lifestyle adjustment, health promotion and prevention | 14.6% | 6.9% | **2.33** | **[1.38;** | **3.93]** | **2.03** | **[1.17;** | **3.51]** | **2.00** | **[1.14;** | **3.50]** |
| Support, helplines and information sources | 10.4% | 4.8% | **2.32** | **[1.29;** | **4.17]** | **2.09** | **[1.15;** | **3.81]** | 1.86 | [0.98; | 3.53] |
| Mental strain | 10.3% | 5.2% | **2.08** | **[1.12;** | **3.88]** | 1.82 | [0.96; | 3.44] | 1.65 | [0.87; | 3.14] |
| Social and legal aspects | 8.0% | 3.3% | **2.55** | **[1.19;** | **5.45]** | **2.30** | **[1.02;** | **5.16]** | 2.02 | [0.90; | 4.49] |
| Scientific surveys and research on diabetes | 6.8% | 2.5% | **2.86** | **[1.26;** | **6.47]** | **2.49** | **[1.09;** | **5.65]** | **2.42** | **[1.04;** | **5.65]** |

Abbreviations as noted in Table 2

DSME-participation were calculated. We performed multiple logistic regression analyses, in which we used DSME-participation as a predictor for the outcomes described above: perceived level of information about diabetes, information needs, information sources, and disease-related distress. Due to their skewed and non-normal distributions, the Likert scaled items regarding perceived diabetes knowledge were dichotomized ("very good" vs. "good or worse") for logistic regression analyses. These zero-order regressions (model 1) were expanded by a stepwise inclusion of the above named sociodemographic (model 2) and disease-related (model 3) confounders. The associations between DSME participation and the above outcomes were assessed based on zero-order predictive margins ($\pi$), odds ratios (ORs) and their respective 95% confidence intervals (95% CIs). All estimates were weighted to compensate for potential deviations between the diabetic sample in the present study and the diabetic reference population obtained from the study "German Health Update" (GEDA) 2012 in terms of sex, age and education structure. Further details of the weighting procedure are described elsewhere [37].

In a sensitivity analysis, multiple imputation by chained equations (m=10) was applied, using a fully conditional specification [47] including all aforementioned variables. The proportion of missing information per variable ranged from 0% to 5.7%. For 23.1% of respondents, at least one value was imputed.

All analyses were performed using STATA version 16.1 (Stata Corp.,

**Table A.2**
Sensitivity analyses of association between DSME-participation and self-reported desire for information on diabetes-related topics based on weighted logistic regression analyses (n = 1396; multiple imputation by chained equations).

| Outcome | | | model 1 | | | model 2 | | | model 3 | | |
|---|---|---|---|---|---|---|---|---|---|---|---|
| | $\pi_{DSME}$ | $\pi_{never}$ | OR | 95%-C.I. | | OR | 95%-C.I. | | OR | 95%-C.I. | |
| Scientific surveys and research on diabetes | 52.7% | 32.8% | **2.28** | **[1.69;** | **3.07]** | **2.07** | **[1.49;** | **2.88]** | **2.08** | **[1.49;** | **2.92]** |
| Treatment/therapy | 51.2% | 46.2% | 1.22 | [0.91; | 1.65] | 1.16 | [0.86; | 1.57] | 1.18 | [0.87; | 1.61] |
| Social and legal aspects | 48.6% | 36.6% | **1.64** | **[1.21;** | **2.21]** | **1.51** | **[1.09;** | **2.08]** | **1.53** | **[1.09;** | **2.15]** |
| Late complications | 47.6% | 38.9% | **1.42** | **[1.06;** | **1.91]** | **1.42** | **[1.05;** | **1.92]** | **1.47** | **[1.07;** | **2.00]** |
| Support, helplines and information sources | 48.5% | 37.0% | **1.60** | **[1.19;** | **2.16]** | **1.55** | **[1.14;** | **2.12]** | **1.62** | **[1.17;** | **2.25]** |
| Acute complications | 45.3% | 34.3% | **1.59** | **[1.18;** | **2.14]** | **1.59** | **[1.17;** | **2.15]** | **1.75** | **[1.27;** | **2.39]** |
| Lifestyle adjustment, health promotion and prevention | 42.9% | 36.8% | 1.29 | [0.95; | 1.74] | 1.22 | [0.88; | 1.69] | 1.32 | [0.94; | 1.86] |
| Diabetes in everyday life | 40.2% | 36.6% | 1.16 | [0.86; | 1.57] | 1.14 | [0.84; | 1.56] | 1.18 | [0.86; | 1.62] |
| Course of the disease | 39.9% | 37.5% | 1.11 | [0.82; | 1.49] | 1.16 | [0.87; | 1.55] | 1.23 | [0.91; | 1.67] |
| Mental strain | 35.9% | 28.5% | 1.40 | [1.00; | 1.97] | 1.31 | [0.94; | 1.83] | 1.29 | [0.92; | 1.80] |
| Causes of diabetes | 35.1% | 36.5% | 0.94 | [0.69; | 1.29] | 1.00 | [0.71; | 1.40] | 1.01 | [0.71; | 1.44] |

Abbreviations as noted in Table 3

**Table A.3**
Sensitivity analyses of association between DSME-participation and sources of information used to learn about diabetes based on weighted logistic regression analyses (n = 1396; multiple imputation by chained equations).

| Outcome | | | model 1 | | | model 2 | | | model 3 | | |
|---|---|---|---|---|---|---|---|---|---|---|---|
| | $\pi_{DSME}$ | $\pi_{never}$ | OR | 95%-C.I. | | OR | 95%-C.I. | | OR | 95%-C.I. | |
| General practitioner | 91.3% | 94.8% | 0.58 | [0.30; | 1.11] | 0.64 | [0.32; | 1.26] | 0.87 | [0.40; | 1.88] |
| Brochures, newspapers, books | 86.5% | 81.2% | 1.48 | [0.99; | 2.21] | 1.51 | [0.99; | 2.30] | 1.53 | [0.98; | 2.38] |
| Diabetologist | 71.8% | 27.4% | **6.75** | **[4.91;** | **9.30]** | **6.44** | **[4.56;** | **9.11]** | **5.34** | **[3.67;** | **7.78]** |
| Radio, TV, DVD | 59.5% | 54.7% | 1.22 | [0.90; | 1.64] | **1.38** | **[1.01;** | **1.89]** | 1.28 | [0.93; | 1.75] |
| Diabetes Care and Education Specialist | 56.9% | 17.3% | **6.31** | **[4.11;** | **9.68]** | **6.02** | **[4.07;** | **8.92]** | **5.24** | **[3.52;** | **7.79]** |
| Websites | 38.8% | 25.8% | **1.83** | **[1.33;** | **2.50]** | **1.56** | **[1.09;** | **2.23]** | **1.66** | **[1.15;** | **2.41]** |
| Pharmacist | 32.9% | 22.7% | **1.62** | **[1.16;** | **2.26]** | **1.70** | **[1.21;** | **2.39]** | **1.52** | **[1.07;** | **2.16]** |
| Acquainted person with diabetes | 29.6% | 24.2% | 1.31 | [0.90; | 1.91] | 1.19 | [0.84; | 1.69] | 1.24 | [0.86; | 1.79] |
| Social networks and forums | 16.9% | 12.4% | 1.44 | [0.94; | 2.20] | 1.22 | [0.76; | 1.95] | 1.23 | [0.77; | 1.99] |
| Other sources of information | 13.5% | 11.3% | 1.22 | [0.79; | 1.87] | 1.15 | [0.74; | 1.77] | 1.15 | [0.74; | 1.79] |
| Support group | 11.3% | 3.9% | **3.13** | **[1.63;** | **6.02]** | **2.98** | **[1.55;** | **5.74]** | **2.80** | **[1.47;** | **5.31]** |
| Diabetes Hotline, Physician Hotline | 10.0% | 14.4% | 0.66 | [0.40; | 1.09] | 0.67 | [0.37; | 1.20] | 0.58 | [0.33; | 1.02] |
| Alternative / naturopathic practitioner | 8.2% | 4.9% | 1.75 | [0.98; | 3.10] | 1.63 | [0.91; | 2.92] | 1.51 | [0.84; | 2.70] |

Abbreviations as noted in Table 4

**Table A.4**
Sensitivity analyses of association between DSME-participation, depressive symptoms (PHQ-2) and diabetes-related emotional distress (PAID-5) based on weighted logistic regression analyses (n = 1396; multiple imputation by chained equations).

| Outcome | | | model 1 | | | model 2 | | | model 3 | | |
|---|---|---|---|---|---|---|---|---|---|---|---|
| | $\pi_{DSME}$ | $\pi_{never}$ | OR | 95%-C.I. | | OR | 95%-C.I. | | OR | 95%-C.I. | |
| High diabetes-related emotional distress(cut-off score of ≥ 8 on the PAID-5) | 15.6% | 12.8% | 1.26 | [0.73; | 2.19] | 1.11 | [0.67; | 1.84] | 0.85 | [0.50; | 1.45] |
| High level of depressive symptoms(cut-off score of ≥ 3 on the PHQ-2) | 18.0% | 19.4% | 0.91 | [0.61; | 1.36] | 0.91 | [0.60; | 1.39] | 0.91 | [0.59 | 1.42] |

College Station, TX).

## 3. Results

### 3.1. Descriptive statistics

Of the 1073 participants included in the analyses, 277 never participated in a DSME (24.2%), while 796 participated in a DSME (75.8%) (Table 1). Both groups had comparable distributions with regard to sex and level of education. However, participants in a DSME training were significantly younger and accordingly more often employed. Further, DSME participants were more likely to have type 1 diabetes, had an initial diagnosis that was comparatively longer ago and were significantly more likely to be treated with insulin and less likely to be treated with OADs than participants who never attended DSME training.

### 3.2. Perceived level of diabetes knowledge

Overall, 27.4% of all DSME participants rated their general diabetes knowledge as "very good", while only 10.9% of never-participants did so (Table 2). When controlling for socio-demographic and disease-related covariates, this group difference also proved to be significant (OR = 2.53). Significant group differences were also confirmed in the following subcomponents of diabetes knowledge: "treatment and therapy" (OR = 2.41), "acute complications" (OR = 1.91) and "diabetes in everyday life" (OR = 1.83).

Also in other areas, DSME participants rated their subjective diabetes knowledge comparatively better than never participants. This concerns the subcomponents: "causes of diabetes", "course of the disease", "late complications", "lifestyle adjustment", "health promotion and prevention", "support, helplines and information sources" and "mental strain". However, when controlling for disease-related confounders, these group differences fell short of the level of statistical significance (OR = 1.57–1.93).

It is worth noting that only 11% of DSME participants and only 4.6% of other respondents felt well informed about mental strains in diabetes.

### 3.3. Diabetes-related information needs

With regard to the predictive margins shown in Table 3, both DSME participants and non-participants generally indicated a high need for information in almost all subtopics of diabetes knowledge. "Treatment/therapy" was the topic on which both DSME-participants as well as never-participants most frequently indicated a need for additional information (π = 53.6% vs. 51.0%).

Moreover, compared to non-participants, DSME-participants more frequently mentioned needs for information related to "scientific surveys and research on diabetes" (π = 56.1%), "social and legal aspects" (π = 51.2%), "support, helplines and information sources" (π = 50.4%), "late complications" (π = 50.9%) and "acute complications" (π = 46.6%). This higher need for information among DSME-participants is also confirmed after adjustment for socio-demographic and disease-related covariates for "scientific surveys and research on diabetes" (OR = 1.80), "late complications" (OR = 1.51) and "acute complications" (OR = 1.71).

### 3.4. Sources of information about diabetes

Regardless of training participation, the GP is the most frequently mentioned source of information (π = 91.7% for DSME participants vs. 95.9% for never-DSME participants), followed by print media (π = 83.5% vs. 86.8%; Table 4). Diabetologists (OR = 5.54; 72.0% vs. 25.6%) and Diabetes Care and Education Specialists (OR = 5.62; π = 58.3% vs. 17.4%), on the other hand, are consulted significantly more often by DSME participants. Other sources of information, such as support groups (OR = 2.85), pharmacists (OR = 1.62) and electronic media (OR = 1.50 for radio, TV, DVD; OR = 1.92 for websites) are also used significantly more often by DSME participants.

### 3.5. Disease distress and level of depressive symptoms

The proportion of people with diabetes who reported increased diabetes-related emotional distress were 13.4% for never-DSME participants and 15.4% for DSME participants (Table 5). The proportion of respondents with a high level of depressive symptoms were 17.9% and 16.9%, respectively.

### 3.6. Sensitivity analysis of imputed data

Sensitivity analyses based on multiple imputation by chained equations largely replicated the results of the previous complete case analyses (Appendix Table A.1–Table A.4). With the exception of "Radio, TV, DVD", all DSME associations were confirmed as significant in the multiple regressions.

## 4. Discussion

The provision of information plays an important role in empowering people with diabetes to perform self-management activities. We present for the first time results of a nationwide population-based study investigating the relationship between participation in DSME and diabetes knowledge, information resources, information needs and disease distress among people with diabetes in Germany.

A key finding of our study is that DSME participants feel better informed in a variety of areas about diabetes than those without DSME training.

Since only about 10% of never-DSME participants reported "very good" knowledge in various categories, these small numbers of participants could lead to concerns about statistical significance. In analyses not presented here, we inspected the subgroup-specific confidence intervals, which did not indicate a deficit in test power.Moreover, our results are in line with international studies [27–33] demonstrating that DSME helps participants to develop the knowledge necessary for effective self-care of diabetes. As knowledge about diabetes has been identified as one of the most important determinants of adherence to the SMB, our findings emphasize the importance of DSME participation. A large amount of unstructured and sometimes contradictory information is a common barrier to information seeking among people with diabetes [48]. Since education programs structure and convey this information, our results underline the importance of a referral for every person with diabetes mellitus in order to increase the knowledge on diabetes-related concerns [22]. Physicians referral to DSME is a major predictor for DSME attendance [49]. Studies on how to increase physicians' referral rates or barriers towards non-referral are still scarce. Future research projects examining this issue might include educational approaches for health care providers about the importance and content of DSME education. Also, as a common physician barrier towards DSME referral is limited consultation time, exploring DSME referral from other health care providers could be helpful. Additionally, financial incentives for physicians to refer to DSME could be explored. Furthermore, clinical decision support tools in the electronic health record (HER) could help to identify patients of need which have not been enrolled so far in a DSME, remind physicians to refer to DSME and monitor the DSME attendance [50]. Mobile health applications as tools to increase patient's diabetes knowledge and facilitate DSME have been shown to successfully lower HbA1c and might be an interesting tool for future diabetes care [51–53].

Another finding of the present study is that DSME participants request additional information about diabetes, especially regarding treatment, therapy, diabetic complications and lifestyle adjustments. Other studies identified similar subjects as important information needs of people with diabetes [12,54]. To further increase patient's diabetes knowledge, these issues should be given greater prominence within DSME as well as in medical consultations as our findings suggested. Also, information about local support groups and existing patient forums by health care providers would be helpful resources to increase patient's diabetes knowledge.

Disease distress poses a great challenge to individual engagement in diabetes SMB [14]. In our study, DSME training was not associated with reduced distress within the present sample both in unadjusted and adjusted analyses. Although the development of healthy coping skills to deal with psychosocial problems is recommended as one of eight core areas of the DSME curriculum time amount in common German DSME curricula [55] dedicated to emotional distress is very limited and coping mechanisms are often unexplored. Furthermore, only a minority of respondents felt well informed about mental strains associated with diabetes. Our findings thus suggest that DSME should take more account of the psychosocial aspects attached to living with diabetes. In particular, education experts might rethink approaches aimed at reducing the burden of living with diabetes and teaching coping mechanisms.

Although diabetologist and diabetes care specialists are clearly more frequently consulted by DSME participants than never-DSME participants, the treating GP remains the most frequently used source of information for people with diabetes. While this underlines the importance of the GP for diabetes treatment, it should be noted that the majority of diabetes type 2 patients in Germany are cared for in the GP practice as standard. Nonetheless, international studies confirm that health professionals play an important role in supporting their patients to cope with complicated information. These publications agree that the treating physician is a key factor for patient empowerment and conclude that, if given the opportunity, physicians might invest more time in educating patients about SMB. Congruent with this, our results suggest that physicians are perceived as particularly important in clarifying ambiguous information about diabetes, regardless of participation in the DSME.

Strengths of the present study include the nationwide, population-based study design and the comprehensive data set, which comprises information on various aspects of diabetes knowledge, information needs and information sources as well as disease-related and

sociodemographic characteristics for people with diabetes across the whole adult age spectrum. However, our data bear the limitations that are inherent of a cross-sectional study design, limiting causal inferences about the effects of DSME. This concerns in particular the associations of DSME participation with higher levels of diabetes knowledge, information needs and consultation of diabetologists. Although we controlled for sociodemographic and disease-related covariates, we cannot rule out that these associations were caused by disease and treatment-related characteristics of DSME participants, who were younger, more likely type 1 diabetics and insulin users than never DSME participants. Since patients with type 1 diabetes or with insulin therapy are usually cared for by a diabetologist or a diabetes care and education specialist, there is a possible selection bias that limits the robustness of the present results. Furthermore, individual attitudes and beliefs about diabetes significantly influence the willingness to participate in DSME. Informed people or people with a high need for information may also be more inclined to attend DSME training. For this reason, knowledge about diabetes should also be considered as a predictor of DSME-participation rather than a mere outcome. Further research using prospective cohort studies would be helpful to address this issue. Another limitation concerns the relatively low response rate of the survey. Although we addressed deviations regarding sociodemographic characteristics by implementing a weighting factor, a selection bias due to non-response cannot be ruled out. Specifically, unaccounted differences between non-responders from survey respondents may have biased the present results. Since the present telephone interview survey relied on self-assessment of diabetes knowledge, effects of social desirability or other systematic biases cannot be excluded. Our data set did not include post-test evaluation or length and duration of DSME. Future studies might utilize more objective, non-reactive measures when assessing the effects of DSME. In particular, follow-up surveys assessing the frequency as well as the total time a patient has received DSME would provide data that can be used to evaluate the effectiveness of DSME on patient's diabetes knowledge more specifically. In this context, it is also worth noting that the relationships examined did not adjust for individual glycaemic control since no blood samples were available. Future research should address this issue in nationwide population-based studies.

In conclusion, our results show that there is a clear need for target group-specific information, especially on psychosocial aspects of diabetes. Treating physicians are important advisors for diabetes-related questions and thus play an important role in translating individual knowledge into self-care behaviour. As disease distress affects treatment success in people with diabetes, DSME should be tailored to address disease distress in order to ensure treatment success.

## Declaration of Competing Interest

The authors declare the following financial interests/personal relationships which may be considered as potential competing interestsC. Heidemann, J. Baumert, Y. Du reports financial support was provided by German Federal Ministry of Health.

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## Appendix

see Appendix Tables A1–A4.

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