"Don't know" answers concerning somatic disease status should not be regarded as "no" responses

"Weiß nicht"-Antworten in Bezug auf Fragen nach dem Vorliegen einer körperlichen Erkrankung sollten nicht als "Nein"-Antworten betrachtet werden

Abstract

Background: With regard to patients' self-reported somatic diseases some researchers transformed “don't know (DK)” responses into “no” responses. The present study examines the appropriateness of this procedure.

Methods: Analyses were based on the nationally representative German National Health Interview and Examination Survey (GHS), which assessed both self-reported diseases and physician-diagnosed diseases (N = 7124). Prevalence rates of persons' DK responses and the corresponding prevalences of physicians' diagnoses were calculated for persons with hypertension, coronary heart disease (CHD), heart failure, asthma, chronic bronchitis, thyroid disease, diabetes, cancer, gout, arthrosis, arthritis and osteoporosis. Correlates of physicians' diagnosed diseases of DK cases are reported.

Results: Between 1.6% and 9.8% of the participants responded with DK to the question of whether they have the disease. In 3.7% to 29.5% of DK cases, the physicians did regard the respective disease as being present. With regard to persons who responded with DK, the probability of a physicians' diagnosis was increased in the case of increased age and a higher number of somatic comorbidities.

Conclusion: The procedure of transforming DK responses into “no” answers does not appear to be recommendable.

Keywords: somatic diseases, validity, self-report

Zusammenfassung

Hintergrund: „Weiß nicht“-Antworten von Patienten auf die Frage nach dem Vorliegen einer körperlichen Erkrankung werden in verschiedenen Studien zu „Nein“-Antworten umkodiert. Die vorliegende Studie untersucht die Validität dieses Vorgehens.

Methodik: Die Studie basiert auf Daten des Bundesgesundheitssurveys 1998 (BGS98), in dessen Rahmen sowohl seitens der Probanden be richtete als auch ärztlich diagnostizierte Erkrankungsangaben vorliegen (N=7124). Untersucht wurden probandenseitig berichtete „weiss nicht“-Antworten im Vergleich zu den Arzt diagnostischen Angaben (liegt vor: ja/nein) in Bezug auf Hypertonie, koronare Herzkrankheit (KHK), Herzinsuffizienz, Asthma, chronisch Bronchitis, Schilddrüserkrankung, Diabetes, Tumor, Gicht, Arthrose, Arthritis und Osteoporose.

Ergebnisse: Zwischen 1,6% und 9,8% der Probanden antworteten mit „weiss nicht“ auf die Frage, ob die entsprechende Erkrankung jemals vorlag. In 3,7% bis 29,5% dieser Fälle diagnostizierte der Arzt die Erkrankung als gegeben. Bei Personen mit DK-Antworten, war die Wahrscheinlichkeit, dass ärztlicherseits eine Erkrankung diagnostiziert wurde, bei älteren Patienten und Patienten mit einer höheren Anzahl somatischer Erkrankungen erhöht.
Schlussfolgerung: Die Umkodierung von „weiß nicht“-Antworten zu „nein“-Antworten erscheint nicht empfehenswert.

Schlüsselwörter: somatische Erkrankungen, Validität, Selbstbericht

Introduction

Epidemiological surveys often assess the somatic health status of a population through self-report questionnaires [1], [2], [3], [4], [5]. Some of these questionnaires include a “don’t know” (DK) answer when asking about the presence of a somatic disease [2], [4], [5]. The issue of how to deal with these DK responses has rarely been examined so far. There are two competing hypotheses [6]: The first regards DK responses as equivalent to the most conservative response. Thus, the DK response is treated and analyzed similarly to the conservative response option. The second hypothesis assumes DK answers to be a middle response. Following this hypothesis, the DK responses should be analyzed separately or omitted in the case of dichotomized analyses (e.g. yes/no). With regard to participants’ disease status (yes/no), one can assume that participants with the disease would have known about it. Thus, some researchers regard a DK response as a “no” [2] [4]. However, as yet there is hardly any evidence as to whether or not this re-coding strategy is justified.

The present study aims to examine this issue using data from the German National Health Interview and Examination Survey (GHS), which assessed the presence of somatic diseases from both patients’ self-report and physicians’ interview. The following questions will be answered:

1. What is the physician-rated disease status of patients who use the DK category?
2. What are the sociodemographic and medical correlates of physician-diagnosed somatic diseases of patients using the DK category?

Methods

Study design and samples

Data were drawn from the German National Health Interview and Examination Survey (GHS) [7]. The GHS was based on a stratified, multistage, cross-sectional, nationally representative sample of subjects aged 18 to 79 years from the non-institutionalized population of Germany. Aims, design and methods have been described in greater detail in a separate publication [5]. Therefore, design and sample characteristics are discussed only briefly here.

The GHS consisted of a stratified random sample from 113 communities throughout Germany with 130 sampling units. A representative gross sample of 13,222 persons was eligible according to the age, sex, and community-type criteria. All participants of the GHS filled out a questionnaire regarding sociodemographic variables, chronic diseases and health-related questions. All participants underwent a thorough physical examination and laboratory data were collected. The response rate (completing the total assessment) was 61.4% (N=7124 [5]).

Assessment

Assessment of somatic diseases

The somatic examination took place in special centers at the study sites and started with a self-report questionnaire to evaluate subjects’ current and past somatic symptoms and complaints, health care utilization, impairments, and disabilities as well as characteristics of the participants. Within the questionnaire, participants were asked the following question: “Which of the following diseases have you had?” followed by a list of 42 disease groups (Table 1) and 2 questions regarding other diseases not mentioned in the list. Each disease question could be answered with “yes”, “no” or “don’t know”. Upon completion of the questionnaire, a structured interview was conducted by a study physician in order to reexamine and refine the medical data from the self-report items. This interview was computer-assisted for standardization and integrity purposes. Diagnoses were then supplemented and, depending on the medical condition, revised on the basis of laboratory test data. Each of the patients’ self-reported disease statuses were re-diagnosed by the study physicians according to whether the disease had been present during the last 4 weeks, the last 12 months or anytime earlier (yes/no). For reasons of conciseness, the results of the present study are restricted to frequent chronic somatic cardiovascular, musculoskeletal, respiratory tract, cancer and endocrinological diseases. Results for all 42 diseases are available from the author on request.

Assessment of sociodemographic, medical and psychosocial correlates

Data such as sex, age and socioeconomic status (SES index with a range from 3 (low) to 21 (high) based on education, income and employment status) were collected within the self-report questionnaire of the GHS. The number of somatic diseases was based on the aforementioned physicians’ diagnoses. To assess psychosocial disturbances, the SF-36-Mental-Health-Index subscale (MHI) was used [8]. Higher scores indicate better mental health, with a range from 0 to 100 points.

Data analysis

The data analysis was completed using Stata Statistical Software™ [9]. Statistical weighting procedures were used
Table 1: Specific somatic diseases assessed

| Disease                                         | “Have you/the patient ever had...?” |
|------------------------------------------------|-------------------------------------|
| Hypertension                                   | High blood pressure, hypertension   |
| Coronary Heart Disease (CHD)                   | Heart circulation disturbances, narrowing of the coronary vessels, angina pectoris |
| Heart attack                                   | Heart attack                        |
| Heart failure                                  | Heart weakness, heart insufficiency  |
| Stroke                                         | Stroke                              |
| Brain circulation disturbance                 | Brain circulation disturbances      |
| Peripheral artery occlusive disease            | Leg circulation disturbances, artery occlusion |
| Varicose veins                                 | Varicose veins                      |
| Vein thrombosis                                | Vein thrombosis                     |
| Asthma                                         | Asthma                              |
| Chronic bronchitis                             | Chronic bronchitis                  |
| Gastritis                                      | Stomach lining inflammation, gastritis |
| Gastric ulcer                                  | Gastric ulcer or duodenal ulcer     |
| Gall bladder disease                           | Gall bladder inflammation or gallstones |
| Liver disease                                  | Shrinking liver, cirrhosis          |
| Liver inflammation                             | Liver inflammation, hepatitis, infectious jaundice |
| Thyroid disease                                | Thyroid disease                     |
| Diabetes with insulin treatment                | Diabetes with insulin treatment     |
| Diabetes without insulin treatment             | Diabetes without insulin treatment  |
| High triglyceride/cholesterol level            | Elevated blood lipids/cholesterol   |
| Anemia, iron deficiency                        | Anemia, iron deficiency             |
| Pyelonephritis                                 | Kidney infection, pyelonephritis    |
| Renal colic                                    | Renal colic, kidney stones          |
| Cancer                                         | Cancer, malignant tumors            |
| Gout                                           | Gout, increase of uric acid         |
| Arthritis                                      | Wear and tear type of arthrosis, arthrosis of the knee or hip, spinal arthrosis |
| Osteoporosis                                   | Osteoporosis                        |
| Migraine                                       | Migraine (viz. recurrent, mostly one-sided sudden headaches, which occur in the morning and last from several hours up to days) |
| Epilepsy                                       | Epilepsy (seizures, cerebral seizures) |
| Parkinson’s disease                            | Parkinson’s disease                 |
| Multiple sclerosis                             | Multiple sclerosis                  |
| Meningitis                                     | Meningitis                          |
| Hay fever                                      | Hay fever, allergic conjunctivitis  |
| Allergic eczema                                | Allergic eczema                     |
| Neurodermatitis                                | Neurodermatitis                     |
| Food allergy                                   | Food allergy                        |
| Allergic hives                                 | Allergic hives                      |
| Gynecological diseases                         | Diseases of the uterus, ovaries or oviduct |

*Diseases marked in bold were incorporated into the present study. Results for the other diseases are available on request.

for post-stratification adjustment to the German Census total by age, sex and region. Correct variance estimates were obtained via the Stata SVY (survey) commands. Correlates of physicians’ diagnosed somatic disease status (yes/no) of DK responses were calculated by means of logistic regression models. Odds ratios (OR) with 95% CI are reported.

Results

Across all diseases 5.4% of the participants responded with DK to the question of whether they have ever been diagnosed with the disease. In 11.4% of the DK cases, the diseases were regarded as present by the physicians. With regard to the specific diseases between 1.6% (cancer) and 9.8% (gout) of the participants responded with DK (Table 2). DK answers were given approximately ⅛ (hypertension) to twice (osteoarthritis) as often as “yes” answers. In 3.7% (osteoarthritis) to 29.5% (arthrosis) of DK cases, the diseases were regarded as present by the physicians. With regard to persons who responded with DK, a physicians' diagnosis of a disease as having been present showed a significant association (p<.05) with covariates in some cases (Table 3). Owing to different sample sizes, these results should be interpreted with caution. However, there seems to be a trend (p<0.2) for older (true for 6 of 12 comparisons) and somatically co-
Table 2: Prevalence rates of yes and don’t know (DK) answers on disease questions (lifetime) as well as physicians’ diagnoses of DK answers

|                          | Self-reported diseases | Physicians' diagnosis in the case of subjects’ “don’t know” answers |
|--------------------------|------------------------|--------------------------------------------------------------------|
|                          | N                      | Yes (%) (95%CI) | DK (%) (95%CI) | N                      | Yes (%) (95%CI) |
| Hypertension             | 6968                   | 21.8 (20.7-22.8) | 5.5 (5.0-6.1)  | 390                    | 16.7 (13.1-21.0) |
| Coronary Heart Disease (CHD) | 6962             | 6.6 (6.0-7.3)   | 8.3 (7.6-9.0)  | 578                    | 5.5 (3.8-7.9)   |
| Heart failure            | 6954                   | 4.5 (3.9-5.0)   | 5.2 (4.6-5.8)  | 347                    | 6.0 (3.7-9.7)   |
| Asthma                   | 6965                   | 7.0 (6.3-7.6)   | 2.6 (2.2-3.1)  | 171                    | 8.6 (5.3-13.7)  |
| Chronic bronchitis       | 6956                   | 8.3 (7.7-9.1)   | 3.0 (2.6-3.5)  | 188                    | 17.1 (11.8-24.1) |
| Thyroid disease          | 6958                   | 14.6 (13.7-15.5)| 3.5 (3.1-4.0)  | 238                    | 25.0 (19.4-31.5)|
| Diabetes without insulin treatment | 6959         | 3.8 (3.3-4.3)   | 1.7 (1.4-2.1)  | 120                    | 8.3 (4.4-15.1)  |
| Cancer                   | 6964                   | 3.8 (3.3-4.3)   | 1.6 (1.3-1.9)  | 115                    | 4.8 (1.4-15.6)  |
| Gout                     | 6954                   | 8.0 (7.3-8.7)   | 9.8 (9.1-10.6)| 697                    | 5.1 (3.6-7.1)   |
| Arthritis                | 6961                   | 28.8 (27.7-30.0)| 8.0 (7.3-8.7)  | 546                    | 29.5 (25.5-33.8) |
| Osteoporosis             | 6922                   | 4.5 (3.9-5.0)   | 8.3 (7.6-9.1)  | 554                    | 3.7 (2.4-5.8)   |

Table 3: Logistic regression model for correlates of physicians’ diagnosed diseases (have been present) in the case of patients’ DK answers

|                      | N | Age per year | Sex female | SES per point | Somatic diseases per comorbidity | MHI per point |
|----------------------|---|--------------|------------|---------------|----------------------------------|---------------|
|                      |   | OR (95%-CI)  | p          | OR (95%-CI)  | OR (95%-CI)                      | OR (95%-CI)   |
| Hypertension         | 238| 1.03 (1.00-1.06)| 0.096 | 1.41 (0.61-3.27)| 0.424 | 1.11 (1.00-1.23) | 0.063 | 1.26 (1.02-1.55) | 0.031 | 1.00 (0.98-1.01) | 0.776 |
| CHD                  | 333| 1.28 (1.11-1.48)| 0.001 | 0.41 (0.09-1.91)| 0.253 | 1.02 (0.88-1.19) | 0.799 | 1.24 (0.97-1.59) | 0.090 | 0.99 (0.96-1.03) | 0.672 |
| Heart failure        | 190| 1.10 (0.92-1.32)| 0.307 | 0.62 (0.09-4.07)| 0.615 | 0.86 (0.64-1.17) | 0.349 | 1.28 (0.90-1.82) | 0.174 | 0.99 (0.95-1.04) | 0.901 |
| Asthma               | 103| 0.97 (0.93-1.01)| 0.161 | 3.36 (0.77-14.56)| 0.105 | 0.97 (0.73-1.28) | 0.616 | 1.06 (0.69-1.62)| 0.780 | 1.05 (1.00-1.10)| 0.076 |
| Chronic bronchitis   | 111| 1.01 (0.96-1.07)| 0.736 | 2.04 (0.53-7.93)| 0.299 | 0.96 (0.83-1.10)| 0.528 | 1.32 (1.04-1.67)| 0.025 | 0.99 (0.96-1.02)| 0.391 |
| Thyroid disease      | 159| 0.98 (0.94-1.01)| 0.123 | 1.99 (0.85-4.88)| 0.113 | 1.11 (1.01-1.22)| 0.028 | 1.13 (0.90-1.41)| 0.296 | 1.01 (0.96-1.03)| 0.613 |
| Diabetes without insulin treatment | 67  | 1.12 (0.97-1.30)| 0.123 | 0.81 (0.04-17.60)| 0.890 | 1.05 (0.85-1.31)| 0.644 | 1.51 (0.96-2.37)| 0.071 | 1.04 (0.97-1.11)| 0.249 |
| Cancer               | 66 | 1.07 (0.92-1.24)| 0.355 | 4.84 (0.22-107.81)| 0.314 | 0.96 (0.78-1.18)| 0.709 | 0.77 (0.49-1.23)| 0.269 | 1.01 (0.96-1.07)| 0.069 |
| Gout                 | 396| 1.05 (1.00-1.09)| 0.046 | 0.16 (0.05-0.54)| 0.004 | 1.00 (0.87-1.16)| 0.980 | 1.25 (1.02-1.53)| 0.029 | 1.01 (0.99-1.03)| 0.276 |
| Arthritis            | 328| 1.03 (1.01-1.05)| 0.006 | 0.67 (0.37-1.22)| 0.189 | 1.03 (0.96-1.10)| 0.428 | 1.35 (1.16-1.57)| 0.000 | 1.00 (0.98-1.02)| 0.770 |
| Arthritis            | 308| 0.99 (0.96-1.03)| 0.756 | 1.00 (0.36-2.74)| 0.999 | 1.00 (0.84-1.20)| 0.943 | 1.27 (1.06-1.51)| 0.010 | 1.00 (0.98-1.04)| 0.666 |
| Osteoporosis         | 323| 1.05 (1.00-1.10)| 0.038 | 6.54 (0.89-49.81)| 0.070 | 1.04 (0.92-1.17)| 0.554 | 1.25 (1.05-1.48)| 0.011 | 1.00 (0.96-1.05)| 0.765 |

n.a. = not applicable

morbid participants (9/12) who responded with DK to be diagnosed as the disease having been present.

**Discussion**

The present study examined for the first time the relationship between patients’ DK responses to questions concerning their disease status and physicians’ diagnosis of the respective disease. When interpreting the results, four limitations of this study should be considered. First, physicians’ diagnoses were neither proven in terms of interrater reliability nor did the physicians had access to patients’ medical records. Hence, there is also a risk of false physicians’ diagnoses. Second, the chronology of the assessment of self-reported and physicians’ dia-
gnosed diseases may have restricted the independency of the measures. However, study physicians were trained to assess a variety of medical conditions in order to increase the reliability and validity of the diagnoses. Third, participants and physicians were asked for lifetime diagnoses, which may have biased the results owing to participants' recall difficulties and the lack of past medical history data. For this reason, we restricted our results to chronic conditions. Fourth, asking for the same information with questions differently worded may yield different responses. Thus, the present results can only be regarded as representative for the question wordings used in the present survey.

In prior studies on patient self-reported diseases some researches transformed DK responses into "no" responses [2], [4]. The rationale for this method is the assumption that participants with a specific disease would have known about this disease. As shown, this procedure causes misclassification, which proved to be of considerable extent at least for some of the diseases examined as well as for older and multimorbid participants, while no such trend were found for age, SES and mental health status. With regard to hypertension, chronic bronchitis, thyroid disease and arthritis, between 16.7% and 29.5% of the patients giving DK responses were diagnosed with the disease by the physician. Moreover, there is a risk of misclassification in the case of infrequent diseases such as osteoporosis (4.5% self-reported "yes") and frequent DK responses (8.3% self-reported "DK"). After recoding the positively diagnosed DK responses, the osteoporosis sample increased from 309 to 330 cases. In a similar vein, this also applies for CHD, heart failure, gout and arthritis. Therefore, the procedure of transforming DK responses into "no" answers does not appear to be recommendable and should at least be discussed as a limitation if there are reasons for keeping the DK responses as no cases within the sample (e.g. small sample size).

With regard to the question of whether a DK response should be included or not within surveys on disease status, there are at least two competing arguments that should be considered. On the one hand, a DK option increases the validity of "yes" and "no" answers and reduce missing data, since only those participants who are certain will answer with yes or no and most others will chose the DK category instead leaving the question unanswered. In this context, it would be of interest to examine the response pattern of DK respondents in the case of forced choice questions (yes/no). On the other hand, omitting the DK option may lead to a higher percentage of substantive responses relative to surveys that offer a DK option [6]. This benefit of forced choice questions, however, has to be balanced against the risk of false-positive and false-negative self-reported disease status. The risk may increase in the case of diseases that often remain undetected such as hypertension, while DK responses to diseases that are not well known may simply lead to non-responses in the case of forced choice questions. Thus, the assessment strategy should take into account the detection rates and the awareness level of a disease as well as sample characteristics such as age and number of comorbidities. Overall, however, including a DK option and excluding cases that responded with DK seems to be the most conservative strategy, reducing misclassification bias to a minimum.

Notes

Conflicts of interest

None declared.

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References

1. Baumeister H, Härter M. Mental disorders in patients with obesity in comparison with healthy probands. Int J Obes. 2007;31(7):1155-64.
2. Gilmer TP, O'Connor PJ, Rush WA, Crain AL, Whitebird RR, Hanson AM, Solberg LI. Impact of office systems and improvement strategies on costs of care for adults with diabetes. Diabetes Care. 2006;29(6):1242-8.
3. Merkin SS, Cavanaugh K, Longenecker JC, Fink NE, Levey AS, Powe NR. Agreement of self-reported comorbid conditions with medical and physician reports varied by disease among end-stage renal disease patients. J Clin Epidemiol. 2007;60(6):634-42.
4. Okura Y, Urban LH, Mahoney DW, Jacobsen SJ, Rodeheffer RJ. Agreement between self-report questionnaires and medical record data was substantial for diabetes, hypertension, myocardial infarction and stroke but not for heart failure. J Clin Epidemiol. 2004;57(10):1096-103.
5. Jacobi F, Wittchen Hu, Höfli C, Sommer S, Lieb R, Höfler M, Pfister H. Estimating the prevalence of mental and somatic disorders in the community: aims and methods of the German National Health Interview and Examination Survey. Int J Methods Psychiatr Res. 2002;11(1):1-18.
6. Groothuis PA, Whitehead JC. Does don’t know mean no? Analysis of “don’t know” responses in dichotomous choice contingent valuation questions. Appl Econ. 2002;34(15):1935-40.
7. Robert Koch-Institut. Public Use File. Bundes-Gesundheitssurvey 1998 - Kernsurvey. Berlin: RKI; 2000.
8. Bullinger M. German translation and psychometric testing of the SF-36 Health Survey: preliminary results from the IQOLA Project. International Quality of Life Assessment. Soc Sci Med. 1995;41(10):1359-66.
9. StataCorp. Stata Statistical Software, release 9.0. College Station, TX: Stata Corporation; 2005.
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