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The activation of professional and personal network relations when experiencing a symptom. A population-based study

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The activation of professional and personal network relations when experiencing a symptom.

A population-based study

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ABSTRACT

Objective(s): To describe patterns of disclosure of symptoms experienced among people in the general population to persons in the personal and/or professional network.

Design: A national population-based cross-sectional study. Data was collected from a web-based survey.

Setting: The general population in Denmark

Participants: 100,000 people randomly selected from the Danish CRS register, representative of the adult Danish population aged ≥ 20 years were invited. 49,706 individuals (men = 23,240; women = 26,466) completed the questionnaire, yielding a response rate of 52.2%. Individuals completing all questions regarding social network relations form the study base (n=44,313).

Primary and secondary outcome measures: Activation of personal and/or professional relations when experiencing a symptom.

Results: The 44,313 individuals reported in total 260,079 symptom experiences within the last four weeks. No professional network relation was used in two thirds of all reported symptoms. The GP was the most frequently reported professional relation activated (22.5%). People reporting to have available personal relations were slightly less inclined to contact the GP (21.9%) when experiencing a symptom compared to people with no reported personal relations (26.8%). The most commonly activated personal relations were *spouse/partner* (56.4%) and *friend* (19.6%). More than a quarter (26.1%) of all reported symptom experiences was not shared with anyone; personal nor professional. The symptom experiences with the lowest frequency of network activation were symptoms such as black stool, constipation, change in stool texture and frequent urination.

Conclusion: This study emphasises variation in the activation of network relations when experiencing a symptom. Symptoms were shared with both the personal and the professional relations, but different patterns of disclosures were discovered. For symptoms derived from the urogenital or colorectal region, the use of both personal and professional relations was relatively small, which might indicate reticence to involve other people when experiencing symptoms from these regions.

Keywords: Signs and symptoms, Social network, Help-seeking behaviour, Primary health care

STRENGTHS AND LIMITATIONS OF THIS STUDY

- This study was based on data from a large cross-sectional nationwide population-based study, inviting 100,000 people randomly selected from the Danish CRS register, representative of the adult Danish population aged 20 years or above.
- The overall concept of the comprehensive questionnaire was to measure the prevalence of self-reported symptom experiences in the general population and explore two dimensions of social network relations, a professional and a personal dimension, respectively.
- Data for the present study were based on individuals who had reported actual experiences of symptoms, thus reflecting true actions rather than hypothetical considerations.
- Telephone interviews offered to participants without access to a computer, a smartphone or a tablet enabled additional responses from the oldest individuals, 80 years or above, who usually are rarely represented in surveys.
- Based on data extracted from the questionnaire, it was not possible to obtain information on the quality or content of the dialogues between the respondents and their relations. We can solely describe whether a relation was activated or not.

INTRODUCTION

The epidemiology of symptom experiences, and what is often referred to as the Symptom Iceberg, referring to the observation that only a minor proportion of all experienced symptoms are shared with a general practitioner, had its breeding ground in the study by Last in the 1960s[1]. Last illustrated that diseases presented to GPs only represent the tip of the iceberg and thus hypothesized that the majority of symptom experiences are managed in a private setting[2]. Contemporary studies also suggest that the majority of symptoms experienced in the general population are not presented to the GP or other healthcare-providers and remain below the so called 'water line'[3-5]. Elliot et al. for example describes that only 12% of symptoms led to a consultation with a primary health professional[3].

Symptom iceberg studies are of relevance because they provide insights into the prevalence of symptom experiences and the social organisation of symptom management. Traditional symptom iceberg studies, however, primarily explored changes of 'the water line' and asked the binary question: did you seek health care or not. We do, only have sparse information on the variety of social encounters individuals engage in when experiencing symptoms, and whether it is possible to identify social patterns of network activation of relevance for understanding how or when people contact the GP. This is of relevance as some research suggests that disclosure of symptoms might affect the timing of the healthcare seeking. A review of factors associated with healthcare seeking for symptoms indicative of serious diseases, such as cancer, has identified a number of triggers; demographic factors (e.g. age, gender), psychological factors (e.g. concern, fear), behavioural factors (e.g. self-medication, watchful waiting) and social relations (e.g. influence of family and friends) [6, 7]. In particular disclosure of a symptom to a family member or friend has been identified as a trigger in favour of seeking medical help with potentially alarming symptoms [8, 9].

Recounting of symptoms to a family member or friend can, however, either prompt or demotivate individuals in the decision to seek medical help, especially within socioeconomic groups and categories of symptoms [5].

In adding to this binary-inspired research on symptom experiences and healthcare seeking, sociologist Pescosolido and colleagues conducted studies exploring patterns of social network activation in relation to

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3 illness episodes[10]. In this approach, contacting the GP with a symptom experienced is not an 'either or' but
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5 potentially part of a larger social pattern. Overall, they showed that there appears to be a limited repertoire
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7 of patterns which are affected by the social setting and medical incidents, which all in one influence the
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9 network opportunities. Inspired by Pescosolido and colleagues' work on social network activation[10], the
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11 objective of this study is to describe patterns of disclosure of symptoms experienced among people in the
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13 general population to persons in the personal and/or professional network in the context of the Danish
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15 welfare state.
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20 **METHOD**

21 **Study design**

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23 This Danish nationwide cross-sectional study comprising a random sample of 100,000 people, representative
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25 of the adult Danish population aged 20 years or above, uses data from the Danish Symptom Cohort, which
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27 has been described previously[11, 12]. Baseline data presented in this paper were collected in a web-based
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29 survey. The data collection was conducted from June to December 2012.
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35 **Subjects and sampling**

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37 All Danish citizens are registered with a unique personal identification number in the Danish Civil
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39 Registration System (CRS), which contains information on any Danish resident's date of birth, gender,
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41 migration, etc. [13]. The sample for this study was randomly selected using the CRS and was invited to
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43 participate in the survey. Each individual received a postal letter explaining the purpose of the study. In the
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45 letter, a unique 12-digit login to a secure webpage was included. This provided access to a comprehensive
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47 web-based questionnaire. In order to prevent the exclusion of people with no access to a computer, a tablet
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49 or a smartphone, the participants were offered the opportunity to respond to the survey in a telephone
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51 interview [11].
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Questionnaire

The overall concept of the questionnaire was to measure the prevalence of self-reported symptom experiences in the general population and explore dimensions related to activation of social networks and healthcare seeking decisions.

In order to explore the prevalence of different symptom experiences, 44 different predefined symptom categories were included based on a review of literature, national and international cancer referral guidelines (4-6). In addition, unspecific general symptoms which often are presented to the GP, e.g. back pain, headache and tiredness, were included.

The questionnaire was pilot- and field-tested and adjusted accordingly. The methodological framework for developing the questionnaire is described in details elsewhere[11].

Items regarding each of the included symptom categories were phrased: "Have you experienced any of the following bodily sensations, symptoms or discomforts within the past four weeks?" For each symptom experience reported, respondents were asked whom they talked to, if any concerning the symptom. Two dimensions of social network relations were explored, a professional and a personal dimension, respectively.

The first item concerning the professional dimension was phrased: "Have you contacted your general practitioner with the symptom or discomfort, in person, by phone or by e-mail?" Afterwards respondents were asked: "Which of the following other healthcare professionals or therapists have you talked to regarding the symptoms or discomforts (through appointment, by telephone or by email)? The following healthcare professionals were selectable: *Another doctor* (practicing specialist, out-of-hours physician or hospital physician), *physiotherapist/chiropractor*, *home help/district nurse*, *pharmacy staff*, *alternative therapist* (e.g. homeopath, healer, reflexologist), *none* and *another* category. The items concerning the personal relations were phrased: "Which of the following members of your family or social network have you talked to about the symptoms or discomforts? The personal relations selectable were *spouse/partner*, *children*, *parents*, *colleague /classmate*, *friend*, *neighbour*, *siblings*, *none* and *another* category. More than one of the relations could be ticked off.

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3 In order to qualify the identification of the personal and professional relations activated when experiencing a
4 symptom, we found it relevant to estimate aspects of social network relations, i.e. whether the respondents
5 had available personal relations or accessibility to other people. For this purpose, the following four items
6 were constructed: 1. "How often are you in contact with friends, acquaintances or family that you do not live
7 with? By contact is meant that you are together, talking with each other on the phone, writing to each other
8 etc." (daily or almost daily / once or twice a week / once or several times a month / less than once a month /
9 Never / I don't know). 2. "If you become ill and need help with practical things, can you count on help from
10 others? (By others is meant people you do not live with)" (Yes, definitely / Yes, maybe /No). 3. "Does it ever
11 happen that you are alone, even if you want to be in the company of others?" (Yes, often / Yes, once in a
12 while / Yes, but rarely / No, never or almost never). 4. "Do you have someone to talk to if you have problems
13 or need support?" (Yes, often / Yes, mostly / Yes, sometimes / No, never or almost never).

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27 On the basis of these four items, individuals were categorised as having an 'available relation' if the following
28 responses were chosen: Often in contact with others (daily or almost daily/ once or twice a week/ once or
29 several times a month), Having available persons who can help (Yes, definitely / Yes, maybe), being alone
30 when desiring to be with others (Never or almost never/ rarely/ once in a while) and having a person to talk
31 to in case of problems (often/ mostly/ sometimes).

32 33 34 35 36 37 38 **Data analysis**

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The data set used in the analyses was constructed by merging all reported symptoms experienced by the
respondents with each individual symptom experience used as study case.

Basic descriptive analyses were used to study the activation of each personal and professional relation when
experiencing a symptom. Activation is somewhat agent-neutral in the sense that data does not allow for
insights into who approached who. This is of particular relevance in respect to the personal relations.
To explore common patterns of relations used when experiencing a symptom, cluster analysis was
performed. These analyses were repeated for the subgroup of people who were categorised as having
available personal relations or accessibility to other people.

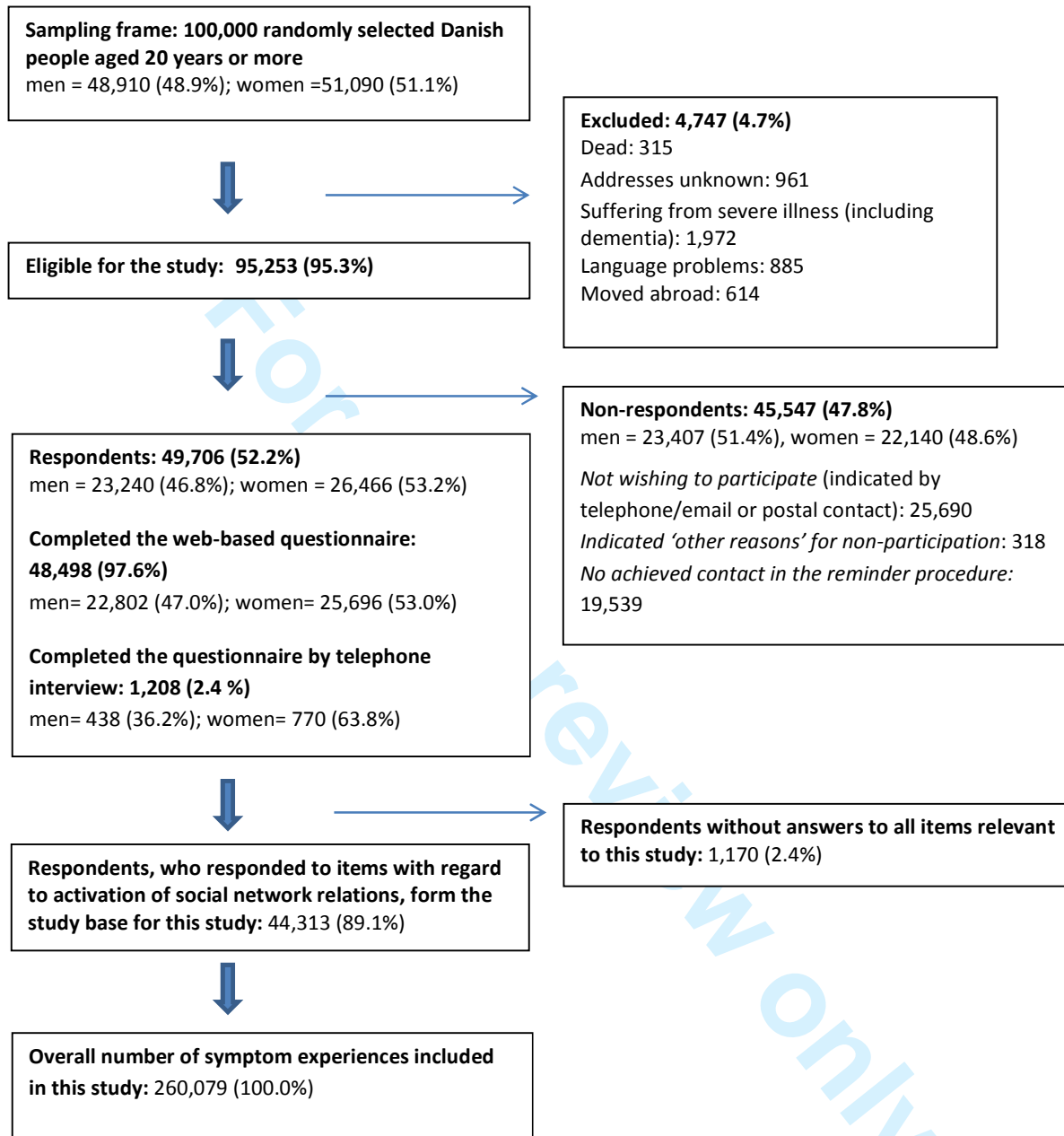
Prevalence's of various combinations of two relations activated when experiencing a symptom were

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3 calculated and displayed in an expanded two times two table. Proportions were calculated as percentages
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5 (%), based on the binominal distribution. For each relation the diagonal across the matrix sums up to 100%.
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7 In order to estimate the proportion of the 44 different symptom experiences with regard to the possible
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9 network relations, three categories of relations were defined; *professional relations*, *personal relations* and
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11 *Neither use of personal nor professional*, respectively. Proportions were calculated as percentages (%), based
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13 on the binominal distribution.
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15 All data analyses were conducted using STATA statistical software 14.1 (StataCorp, College Station, TX, USA).
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20 RESULTS

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22 Of the 100,000 randomly selected individuals invited to participate, 49,706 individuals completed the
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24 questionnaire, yielding a response rate of 52.2%. Some 1,208 (2.4%) completed the questionnaire by
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26 telephone interview (figure 1). The respondents were fairly representative of the study sample according to
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28 ethnicity, socioeconomic and demographic variables. Full details of response rate, participant characteristics
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30 and symptom prevalence have been described in details elsewhere [12].
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Figure 1: Study sample



Personal and professional relations activated when experiencing a symptom

A total of 44,313 individuals answered all the relevant items with regard to activation of social network relations and form the basis for this study, Figure 1. They reported a total of 260,079 symptoms (Table 1).

For 78,214 (30.1%) of all symptom experiences, no personal relation was activated. The most commonly activated personal relation was a *spouse/partner*, who was activated in 56.4% of the symptom experiences,

followed by *friends* (19.6%). No professional network relation was activated in 172,148 (66.2%) of the symptom experiences. The most frequently reported professional relation was the *GP*, who was contacted for 22.5% of the symptom experiences (Table 1).

Table 1. Descriptive overview of study sample with regard to symptom experiences and reported relations.

	Study sample		Number of symptoms	
	N	(%)	n	(%)
Study sample				
<i>Overall</i>	44,313	(100.0)	260,079	(100.0)
Gender				
<i>Men</i>	20,546	(46.4)	107,192	(41.2)
<i>Women</i>	23,767	(53.6)	152,887	(58.7)
Age				
<i>20-39</i>	11,262	(25.4)	77,870	(29.9)
<i>40-59</i>	18,224	(41.1)	106,195	(40.8)
<i>60-79</i>	13,641	(30.8)	68,806	(26.5)
<i>80+</i>	1,186	(2.7)	7,208	(2.8)
Personal relation				
<i>Spouse/partner</i>			146,745	(56.4)
<i>Children</i>			31,177	(12.0)
<i>Parents</i>			29,290	(11.3)
<i>Colleague/classmate</i>			28,335	(10.9)
<i>Friend</i>			51,065	(19.6)
<i>Neighbour</i>			6,537	(2.5)
<i>Sibling</i>			3,279	(1.3)
<i>None</i>			78,214	(30.1)
<i>Other</i>			2,692	(1.0)
Professional relation				
<i>General practitioner</i>			58,504	(22.5)
<i>Another doctor</i>			41,539	(16.0)
<i>Physiotherapist/chiropractor</i>			12,456	(4.8)
<i>Home help/district nurse</i>			2,611	(1.0)
<i>Pharmacy staff</i>			3,754	(1.4)
<i>Alternative therapist</i>			9,455	(3.6)
<i>None</i>			172,148	(66.2)
<i>Other</i>			6,927	(2.7)

Patterns of network activation

When merging all relations into one source of network including both professional and personal relations, nearly 3,000 different patterns of relations occurred for the 260,079 symptoms reported. The twenty most activated patterns of relations are listed in Table 2. The most prevalent pattern was the activation of no

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3 relations. More than a quarter (26.1%) of all reported symptom experiences was not shared with anyone;
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5 neither personal nor professional. Disclosure of symptoms to one's *spouse/partner* was almost consistently
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7 occurring throughout the first ten patterns, standing alone or in combination with either a professional
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9 relation or another personal relation. Involving both personal and professional relations by activating a
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11 *spouse/partner* and the *GP* was the third most common pattern of network relations (Table 2).

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14 Even though 2,975 patterns occurred, two thirds of all symptom experiences were represented in the first
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16 ten patterns of relations. This contributes to a limited repertoire of patterns of relations, most of them
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18 pluralistic and some single (Table 2).

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20 For the subgroup of respondent who reported to have an available network of relations small differences
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22 were seen in the patterns of relations compared to those of the full sample. A tendency towards higher
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24 activation of personal relations and less activation of both the GP and other doctors was seen in this group.

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26 Furthermore, this group was less inclined to contact the GP (21.9%) when experiencing a symptom
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28 compared to people without an available network of relations or accessibility to other people (26.8%) (Table
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31 2).

Table 2. The most frequent patterns of relations reported with regard to a symptom experience.

Patterns of relations	Full sample (n=260,079)		Subgroup with available relations* (n=226,013)	
	n (%)	Rank	n (%)	Rank ¹
None	67,774 (26.1)	1	57,625 (25.4)	1
Spouse/partner	61,050 (23.5)	2	55,307 (24.4)	2
Spouse/partner + GP	8,773 (3.4)	3	7,763 (3.4)	3
Spouse/partner + GP + Another doctor	7,188 (2.8)	4	6,110 (2.7)	4
Friend	6,270 (2.4)	5	5,463 (2.4)	5
Spouse/partner + Friend	4,877 (1.9)	6	4,524 (2.0)	6
Spouse/partner + Another doctor	4,479 (1.7)	7	3,876 (1.7)	7
GP	3,898 (1.5)	8	2,885 (1.3)	10
Spouse/partner + Colleague	3,601 (1.4)	9	3,360 (1.5)	8
Spouse/partner + Children	3,504 (1.4)	10	3,183 (1.4)	9
Spouse/partner + Parent	2,816 (1.1)	11	2,567 (1.1)	11
Parent	2,630 (0.7)	12	2,171 (1.0)	12
Colleague	1,931 (0.7)	13	1,679 (0.7)	13
Spouse/partner + Children + GP + Another doctor	1,845 (0.7)	14	1,614 (0.7)	15
Children	1,839 (0.7)	15	1,440 (0.6)	16
Spouse/partner + Colleague + Friend	1,775 (0.7)	16	1,675 (0.7)	14
Another doctor + GP	1,693 (0.7)	17	1,226 (0.5)	21
Another doctor	1,660 (0.6)	18	1,280 (0.6)	18
Spouse/partner + Parent + Friend	1,410 (0.5)	19	1,311 (0.6)	17
Spouse/partner + Children + GP	1,397 (0.5)	20	1,241 (0.5)	20
Spouse/partner + Physiotherapist/chiropractor	1,382 (0.5)	21	1,264 (0.6)	19

*Respondents reporting available personal relations or accessibility to other people.

¹ Rank according to the sub analysis with respondents who have reported available personal relations or accessibility to other people.

Density of patterns

The figures highlighted in bold in table 3 represent the patterns with high densities across each cluster of two relations using an arbitrary cut-off at 50% level [10]. For each relation, the diagonal across the matrix sums up to 100%. The main collaborator in the patterns comprising the GP was the *spouse/partner* (70.9%). This means that when the GP is contacted with regard to a symptom experience, the *spouse/partner* is involved in 70.9% of the cases. Conversely, when the *spouse/partner* was activated with regard to a symptom experience, the GP was only involved in less than one third of the cases (28.3%). Across all possible relations listed in table 3, the *spouse/partner* was one of the main relations to be activated when experiencing a symptom. When a more distant personal relation such as a *neighbour* or *colleague* was activated, it was often in combination with various different relations. This is opposite to the patterns

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3 including a *spouse/partner*, who was often activated as a single relation or in combination with limited close
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5 relations. When a professional relation was activated, it was often in combination with a GP. Looking at the
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7 patterns comprising *none personal relations* the most activated relation was the GP (8.1%) (Table 3).
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Table 3: Density for patterns of both professional and personal relation (n(%)). Enhanced two times two table with all relations included.

Relations	Spouse/partner	Children	Parents	Colleague/ classmate	Friend	Neighbour	Sibling	General practitioner	Another doctor	Physiotherapist / chiropractor	Home help/ district nurse	Pharmacy staff	Alternative therapist	None personal relation	None prof. relation
Spouse/partner	146,745(100.0)	22,254(15.2)	19,109(13.0)	20,489(14.0)	30,548(20.8)	4,475(3.0)	1,395(1.0)	41,479(28.3)	30,569(20.8)	9,476(6.5)	1,294(0.9)	2,503(1.7)	6,588(4.5)	0(0.0)	85,250(58.1)
Children	22,254(71.4)	31,177(100.0)	5,744(18.4)	7,383(23.7)	12,971(41.6)	3,635(11.7)	622(2.0)	15,319(49.1)	12,029(38.6)	4,139(13.3)	1,021(3.3)	894(2.9)	2,277(7.3)	0(0.0)	10,183(32.7)
Parents	19,109(65.2)	5,744(19.6)	29,290(100.0)	9,953(34.0)	15,712(53.6)	2,081(7.1)	758(2.6)	11,339(38.7)	8,439(28.8)	3,263(11.1)	416(1.4)	930(3.2)	2,437(8.3)	0(0.0)	12,598(43.0)
Colleague/ classmate	20,489(72.3)	7,383(26.1)	9,953(35.1)	28,335(100.0)	15,720(55.5)	2,653(9.4)	563(2.0)	9,817(34.6)	6,976(24.6)	3,677(13.0)	291(1.0)	760(2.7)	2,406(8.5)	0(0.0)	13,632(48.1)
Friend	30,548(59.8)	12,971(25.4)	15,712(30.8)	15,720(30.8)	51,065(100.0)	4,627(9.1)	1,222(2.4)	19,258(37.7)	14,501(28.4)	5,433(10.6)	836(1.6)	1,396(2.7)	4,376(8.6)	0(0.0)	22,682(44.4)
Neighbour	4,475(68.5)	3,635(55.6)	2,081(31.8)	2,653(40.6)	4,627(70.8)	6,537(100.0)	158(2.4)	3,435(52.5)	3,003(45.9)	1,265(19.4)	266(4.1)	284(4.3)	733(11.2)	0(0.0)	1,674(25.6)
Sibling	1,395(42.5)	622(19.0)	758(23.1)	563(17.2)	1,222(37.3)	158(4.8)	3,279(100.0)	1,330(40.6)	900(27.4)	234(7.1)	133(4.1)	73(2.2)	152(4.6)	0(0.0)	1,370(41.8)
General practitioner	41,479(70.9)	15,319(26.2)	11,339(19.4)	9,817(16.8)	19,258(32.9)	3,435(5.9)	1,330(2.3)	58,504(100.0)	26,921(46.0)	6,388(10.9)	1,237(2.1)	1,801(3.1)	3,903(6.7)	6,370(10.9)	0(0.0)
Another doctor	30,569(73.6)	12,029(29.0)	8,439(20.3)	6,976(16.8)	14,501(34.9)	3,003(7.2)	900(2.2)	26,921(64.8)	41,539(100.0)	4,391(10.6)	875(2.1)	1,192(2.9)	2,813(6.8)	3,827(9.2)	0(0.0)
Physiotherapist/ chiropractor	9,476(76.1)	4,139(33.2)	3,263(26.2)	3,677(29.5)	5,433(43.6)	1,265(10.2)	234(1.9)	6,388(51.3)	4,391(35.3)	12,456(100.0)	363(2.9)	429(3.4)	2,100(16.9)	887(7.1)	0(0.0)
Home help/ district nurse	1,294(49.6)	1,021(39.1)	416(15.9)	291(11.1)	836(32.0)	266(10.2)	133(5.1)	1,237(47.4)	875(33.5)	363(13.9)	2,611(100.0)	212(8.1)	144(5.5)	307(11.8)	0(0.0)
Pharmacy staff	2,503(66.7)	894(23.8)	930(24.8)	760(20.2)	1,396(37.2)	284(7.6)	73(1.9)	1,801(48.0)	1,192(31.8)	429(11.4)	212(5.6)	3,754(100.0)	514(13.7)	400(10.7)	0(0.0)
Alternative therapist	6,588(69.7)	2,277(24.1)	2,437(25.8)	2,406(25.4)	4,376(46.3)	733(7.8)	152(1.6)	3,903(41.3)	2,813(29.8)	2,100(22.2)	144(1.5)	514(5.4)	9,455(100.0)	1,163(12.3)	0(0.0)
None personal relation	0(0.0)	0(0.0)	0(0.0)	0(0.0)	0(0.0)	0(0.0)	0(0.0)	6,370(8.1)	3,827(4.9)	887(1.1)	307(0.4)	400(0.5)	1,163(1.5)	78,214(100.0)	67,774(86.7)
None prof. relation	85,250(49.5)	10,183(5.9)	12,598(7.3)	13,632(7.9)	22,682(13.2)	1,674(1.0)	1,370(0.8)	0(0.0)	0(0.0)	0(0.0)	0(0.0)	0(0.0)	0(0.0)	67,774(39.4)	172,148(100.0)

Patterns for each possible relation must be read horizontal e.g. all pattern involving *spouse/partner* (146,745; 100%) are combined with children in 15.2% of the symptom experiences, etc.

For each relation the diagonal across the matrix sum up to 100%.

Bold, black = cutoff $\geq 50\%$

Type of symptom and network activation

The symptoms with the highest proportion of activation of neither personal nor professional relations were symptoms such as *black stool*, *constipation* and *change in stool texture*. The proportion of activating a professional relation was highest for *blood in urine*, *shortness of breath* and *back pain*. Personal relations were most often used when experiencing *back pain*, *repeated vomiting*, *feeling unwell* and *tiredness*. *Back pain* was the symptom which overall activated most relations, as only 8.8% of all experienced *back pains* were kept to oneself (Table 4).

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Table 4: The proportion of contacts to professional, personal and “neither use of personal nor professional” relation with regard to the 44 different symptom experiences. The total number of symptom experiences was 260,079.

Type of symptom	Number of symptoms <i>N</i>	Use of professional relations <i>n (%)</i>	Use of personal relations <i>n (%)</i>	Neither use of personal nor professional <i>n (%)</i>
Tiredness	23,880	8,040 (33.7)	19,505 (81.7)	3,890 (16.3)
Night-time urination	23,337	4,565 (19.6)	14,266 (61.1)	8,456 (36.2)
Lack of energy	17,952	5,878 (32.7)	14,026 (78.1)	3,460 (19.3)
Headache	17,564	6,438 (36.6)	13,135 (74.8)	3,900 (22.2)
Back pain	15,474	10,809 (69.8)	13,478 (87.1)	1,363 (8.8)
Abdominal bloating	14,238	3,627 (25.5)	9,074 (63.7)	4,687 (32.9)
Memory problems	9,480	3,010 (31.7)	7,345 (77.5)	1,903 (20.1)
Abdominal pain	9,365	4,150 (44.3)	7,434 (79.4)	1,627 (17.4)
Coughing	8,535	2,899 (33.9)	5,579 (65.4)	2,575 (30.2)
Concentration problems	8,728	2,972 (34.1)	5,817 (69.6)	2,240 (26.8)
Change in stool texture	8,207	2,216 (27.0)	4,049 (49.3)	3,662 (44.6)
Dizziness	7,604	3,570 (46.9)	5,687 (74.8)	1,592 (20.9)
Feeling unwell	7,160	2,814 (39.3)	5,954 (83.2)	984 (13.7)
Constipation	6,980	1,885 (27.0)	3,251 (46.6)	3,279 (47.0)
Increase in waist circumference	6,308	1,385 (22.0)	4,195 (66.5)	1,928 (30.6)
Change in stool frequency	6,199	1,654 (26.7)	3,232 (52.1)	2,632 (42.5)
Diarrhoea	6,184	1,730 (28.0)	3,401 (55.0)	2,469 (39.9)
Nausea	6,007	2,098 (34.9)	4,559 (75.9)	1,248 (20.8)
Swollen legs	5,850	3,154 (53.9)	4,342 (74.2)	1,112 (19.0)
Difficulty in emptying the bladder	5,546	2,106 (38.0)	2,935 (52.9)	2,143 (38.6)
Frequent urination	5,024	1,836 (36.5)	3,108 (61.9)	1,616 (32.2)
Stress incontinence	4,658	1,352 (29.0)	2,633 (56.5)	1,765 (37.9)
Erectile dysfunction*	4,161	1,743 (41.8)	3,030 (72.8)	909 (21.8)
Pelvic pain*	3,848	1,505 (39.1)	2,595 (67.4)	1,081 (28.1)
Shortness of breath	3,789	2,520 (66.5)	2,994 (79.0)	537 (14.2)
Hoarseness	3,654	1,036 (28.3)	2,227 (60.9)	1,264 (34.6)
Urge incontinence	2,952	1,118 (37.9)	1,861 (63.0)	897 (30.4)
Loss of appetite	2,949	902 (30.6)	1,900 (64.4)	922 (31.3)
Blood in stool/rectal bleeding	2,191	1,002 (45.7)	1,267 (57.8)	744 (34.0)
Pelvic pain during intercourse*	2,037	784 (38.5)	1,609 (79.0)	359 (17.6)
Fever	1,905	642 (33.7)	1,507 (79.1)	324 (17.0)
Difficulty swallowing	1,645	818 (49.7)	1,215 (73.9)	340 (20.7)
Weight loss	1,407	520 (37.0)	1,044 (74.2)	314 (22.3)
Incontinence without stress/urge	1,102	547 (49.6)	654 (59.3)	332 (30.1)
Pain/burning when urinating	997	594 (59.6)	654 (65.6)	243 (24.4)
Lump/swollen lymph nodes	784	413 (52.7)	543 (69.3)	185 (23.6)
Black stool	740	194 (26.2)	246 (33.2)	429 (58.0)
Vaginal bleeding after intercourse*	600	258 (47.5)	456 (76.0)	110 (18.3)
Repeated vomiting	600	300 (50.0)	502 (83.7)	75 (12.5)
Postmenopausal bleeding*	342	156 (45.6)	217 (63.5)	99 (28.9)
Blood in urine	272	233 (85.7)	217 (79.8)	27 (9.9)
Blood in semen*	90	57 (63.3)	51 (56.7)	27 (30.0)
Coughing up blood	59	35 (59.3)	41 (69.5)	13 (22.0)
Blood in vomit	43	20 (46.5)	30 (69.8)	12 (27.9)

*Gender specific symptoms.

DISCUSSION

Article summary

Symptoms are shared with both the personal and the professional network, but different patterns of disclosures were discovered. More than a quarter of all reported symptom experiences were not shared with anyone; personal nor professional. Whether having an available network or not, the GP was the most frequently reported professional relation activated, although people reporting to have available network relations were slightly less inclined to contact their GP. Across all possible relations, the spouse/partner was the main relation to be activated when experiencing a symptom and involved in the main part of symptoms also shared with the GP.

The study also emphasises variation in disclosure of different symptoms. For symptoms derived from the urogenital or colorectal region, the use of both personal and professional relations was relatively small, which might indicate reticence to involve other people when experiencing symptoms that might be subject to stigmatization, embarrassment or shame.

Strengths and limitations

This study was a large cross-sectional nationwide population-based study, inviting 100,000 people randomly selected from the Danish CRS register, representative of the adult Danish population aged 20 years or above. To our knowledge, such a large-scale nationwide population-based study, investigating a wide range of self-reported symptom experiences and dimensions related to network activation, has not previously been conducted.

The response rate of 52.2% was comparable or even higher compared to previous surveys measuring symptom prevalence in the general population [3, 14]. Although a preponderance of the respondents was women, and the respondents were slightly older than the non-respondents, the respondents were fairly representative of the general Danish population. However, differences between the respondents and the

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3 non-respondents regarding other parameters, which might include a risk of over- or underestimating the
4 proportion of GP contacts, cannot be eliminated. For more details, see Elnegaard et al.[12].
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8 To avoid a possible selection bias due to the web-based design of the questionnaire, participants without
9 access to a computer, a smartphone or a tablet were offered the possibility of conducting the survey as a
10 telephone interview. These interviews enabled additional responses from the oldest individuals, aged 80
11 years or above, who usually are rarely represented in surveys.
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15 The participants were asked to recall symptom experiences within the preceding four weeks and whether
16 they had contacted a personal or professional relation with these symptoms at any time. Recall bias cannot
17 be completely eliminated in questionnaire studies [15]. Some may misplace older symptom experiences in
18 the specified timeframe due to the severity of symptoms, or because they had contacted a GP about them
19 [16]. Others may have forgotten about a symptom experience or a GP contact, because the symptom turned
20 out to be nothing to worry about or simply due to memory decay [17]. The recall period of four weeks was
21 chosen to ensure getting enough symptom experiences to obtain statistically precise estimates, even for rare
22 symptoms, while still assuming that individuals could recall symptoms and whom they talked to or contacted
23 fairly accurately [18, 19].
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36 The term symptom as presented in the discipline of biomedicine is influenced by a desire to predict
37 underlying diseases and risks of negative effects on health. From the biomedical perspective, it is common to
38 distinguish between subjective health complaints (symptoms) and signs with the latter being objectively
39 verifiable (e.g. blood in the urine or jaundice), whereas symptoms often refer to subjective complaints. The
40 WONCA Dictionary of General/Family Practice defines a symptom as “any subjective evidence of a health
41 problem as perceived by the patient”[20]. This definition implies that symptom experiences are not viewed
42 as objective, clinical phenomena, but are seen as the result of the patient’s own interpretation process, in
43 which bodily sensations or changes are transformed into signs of ill health [21-23]. Accordingly, we defined
44 subjectively reported symptom experiences as multidimensional constructions embedded in a complex
45 interplay of biological, psychological, and cultural factors, and interpreted the symptom experiences
46 reported in the survey as reflections of the individually experienced responses to bodily changes or
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5 When using data extracted from a questionnaire-based survey certain limitations occur, among others it
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7 does not allow insights into what kinds of bodily sensation are potentially included by respondents as
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9 symptoms or not[23]. Following this line of reflection, it was not possible to obtain data on the quality or
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11 content of the dialogues between the respondents and their relation. Furthermore, it was not possible to
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13 obtain information regarding the chronological order of the activation of relations either. We can solely
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15 describe whether a relation was activated or not.
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18 19 20 **Comparison with existing literature**

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22 In the present study, more than one fifth of the symptom experiences were shared with the GP. This result is
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24 lower compared to Pescosolido [10], who found that the GP was involved in 85.4% of the illness episodes
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26 registered in a retrospective survey. The high utilisation of the GP found in the paper of Pescosolido[10] was
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28 expected as the study selected episodes of illness on the basis of e.g. severity and recency. Furthermore, the
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30 present study was conducted in a gate-keeper-system with free access to the GP [24] which could
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32 theoretically increase the use of the GP compared to the American health system described in
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34 Pescosolido[10]. On the contrary, the findings in the present study were derived from a random sample in an
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36 unselected population reporting symptom experiences.
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40 More than a fourth of the symptom experiences reported did not result in activation of neither a personal
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42 nor a professional relation. This finding was lower compared to a recent study performed (48.6%)[3], but
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44 generally consistent with studies conducted earlier [25-27]. Moreover, the overall proportion of GP
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46 activation was higher compared to similar studies conducted [3, 25, 26].
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49 Within the present study the most activated personal relation was the *spouse/partner*, who was involved in
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51 more than half of all the symptoms reported. The fact that the *spouse/partner* was activated when people
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53 experienced a symptom was not surprising but an interesting aspect in the present study was the fact that
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55 only a quarter of all the symptoms discussed with the *spouse/partner* was also presented to the GP, whereas
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57 the symptoms discussed with the GP had also been discussed with the *spouse/partner* in almost three
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3 quarters of the symptom experiences. These findings could indicate that the personal relation can act as a
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5 trigger of healthcare seeking. Moreover, the results underline that many symptoms are still kept below the
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7 'water-line' of the symptom iceberg.
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10 Various readings of these findings may be presented. It has been suggested that the social management of
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12 illness in welfare states is increasingly institutionalised and professionalised[28]. This would explain why
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14 people in our study to a high degree seek medical assistance when experiencing symptoms and perhaps also
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16 why people seem hesitant in activating personal networks. Overall, it may suggest a form of privatisation of
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18 the body, and the results are illustrative of how authority in the social management of illness is increasingly
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20 placed in the professional sector.
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24 Nearly 3,000 different patterns of activated relations with regard to a symptom experience were revealed in
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26 the present study, but the density within the first five patterns accounted for nearly 60% of all patterns. This
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28 was in line with Pescosolido[10], who concludes that there appears to be a limited repertoire of patterns of
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30 choice, most of them pluralistic and some single.
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32 Furthermore, Pescosolido [10] only found few factors influencing which relations were activated when
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34 experiencing an illness episode. That was social characteristics, which differentiated the strategies activated
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36 but not whether the GP was contacted. In the present study, people without an available personal network
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38 of relations more often activated the GP when compared to people with a potential social network.
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40 Moreover, some of the variation found in the activation of network relations might be explained by a
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42 difference in the characteristics of the symptom and the symptom categories. The present study comprises
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44 44 quite diverse symptom categories contrary to studies only comprising few alarm symptoms of cancer [29,
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46 30]. We found a tendency of solitariness or a higher proportion of not activating a network relation with
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48 regard to symptoms originated from the urogenital or colorectal region. This corresponds to findings from
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50 the cancer literature, where change in bowel and bladder habits was associated with a longer patient
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52 interval [8] often due to embarrassment, fear or taboo[6].
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IMPLICATIONS FOR RESEARCH AND PRACTICE

This study adds insights into the knowledge about healthcare seeking and social network by exploring two dimensions of social variation in network activation and use of GP. Reasons for no activation of a network relation when experiencing a symptom can be that, people either intentionally chose not to activate any in their social network or that people have no access to a social network of relations. In this population-based setting, we found that more than a quarter of all reported symptom experiences are not shared with anyone; personal nor professional regardless of accessibility to social network relations.

The present study speaks in favour of that the social management of illness has been increasingly institutionalised, as people with sparse access to personal network relations make use of the GP to a greater extend, which additionally stresses the GP's role with regard to people without available social network relations and in general.

For symptoms derived from the urogenital or colorectal region, the activation of either personal or professional relations was relatively low, which might indicate reticence to involve other people when experiencing symptoms from these bodily regions. Further research into the characteristics of potential barriers towards contacting the GP with a symptom derived from these body regions would be useful in order to accommodate issues of importance for contacting a GP.

FUNDING

The study is financially supported by the Novo Nordisk Foundation and the Danish Cancer Society. The entire funding source had no involvement in the study or in the approval of the manuscript.

ETHICAL APPROVAL

The Regional Scientific Ethics Committee for Southern Denmark evaluated the project and concluded that no further approval was necessary due to Danish legislation. The participants in the study were clearly informed that there would be no clinical follow-up, and that they should contact their own GP in case of concern or worry. The project was approved by the Danish Data Protection Agency (journal no. 2011-41-6651).

COMPETING INTEREST STATEMENT

The authors declare that they have no competing interests.

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DATA SHARING STATEMENT

The datasets generated and analysed during the current study are not publicly available due to the data protection regulations of the Danish Data Protection, Statistics Denmark and the Danish Health and Medicines Authority. Access to data is strictly limited to the researchers who have obtained permission for data processing. This permission was given to the Research Unit of General Practice, Department of Public Health, University of Southern Denmark.

CONTRIBUTORSHIP STATEMENT

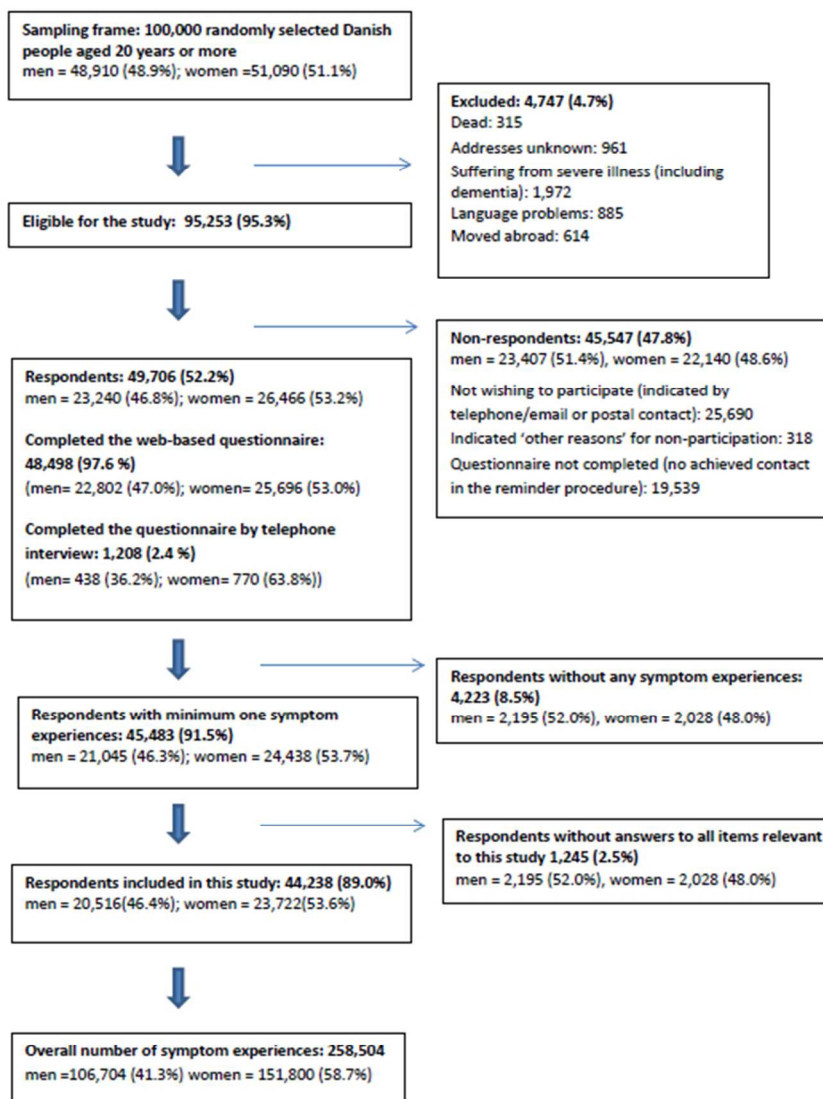
SE and DJ participated in the design of the study, development of the questionnaire, the logistics concerning the survey and the drafting of the manuscript. SE moreover did the main work in forming the manuscript and carried out the statistical analyses. RSA and AFP participated in the design of the study, development of the questionnaire and drafting of the manuscript. MMS and RdC participated in the statistical considerations concerning the survey and analyses and MMS carried out the statistical analyses. All authors read and approved the final manuscript.

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Figure 1: Study cohort



Study sample

205x264mm (72 x 72 DPI)

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Table 3: Density for patterns of both professional and personal relation (n(%)). Enhanced two times two table with all relations included.

Relations	Spouse/ partner	Children	Parents	Colleague/ classmate	Friend	Neighbour	Sibling	General practitioner	Another doctor	Physiotherapist / chiropractor	Home help/ district nurse	Pharmacy staff	Alternative therapist	None personal relation	None prof. relation
Spouse/partner	146,745(100.0)	22,254(15.2)	19,109(13.0)	20,489(14.0)	30,548(20.8)	4,475(3.0)	1,395(1.0)	41,479(28.3)	30,569(20.8)	9,476(6.5)	1,294(0.9)	2,503(1.7)	6,588(4.5)	0(0.0)	85,250(58.1)
Children	22,254(71.4)	31,177(100.0)	5,744(18.4)	7,383(23.7)	12,971(41.6)	3,635(11.7)	622(2.0)	15,319(49.1)	12,029(38.6)	4,139(13.3)	1,021(3.3)	894(2.9)	2,277(7.3)	0(0.0)	10,183(32.7)
Parents	19,109(65.2)	5,744(19.6)	29,290(100.0)	9,953(34.0)	15,712(53.6)	2,081(7.1)	758(2.6)	11,339(38.7)	8,439(28.8)	3,263(11.1)	416(1.4)	930(3.2)	2,437(8.3)	0(0.0)	12,598(43.0)
Colleague/ classmate	20,489(72.3)	7,383(26.1)	9,953(35.1)	28,335(100.0)	15,720(55.5)	2,653(9.4)	563(2.0)	9,817(34.6)	6,976(24.6)	3,677(13.0)	291(1.0)	760(2.7)	2,406(8.5)	0(0.0)	13,632(48.1)
Friend	30,548(59.8)	12,971(25.4)	15,712(30.8)	15,720(30.8)	51,065(100.0)	4,627(9.1)	1,222(2.4)	19,258(37.7)	14,501(28.4)	5,433(10.6)	836(1.6)	1,396(2.7)	4,376(8.6)	0(0.0)	22,682(44.4)
Neighbour	4,475(68.5)	3,635(55.6)	2,081(31.8)	2,653(40.6)	4,627(70.8)	6,537(100.0)	158(2.4)	3,435(52.5)	3,003(45.9)	1,265(19.4)	266(4.1)	284(4.3)	733(11.2)	0(0.0)	1,674(25.6)
Sibling	1,395(42.5)	622(19.0)	758(23.1)	563(17.2)	1,222(37.3)	158(4.8)	3,279(100.0)	1,330(40.6)	900(27.4)	234(7.1)	133(4.1)	73(2.2)	152(4.6)	0(0.0)	1,370(41.8)
General practitioner	41,479(70.9)	15,319(26.2)	11,339(19.4)	9,817(16.8)	19,258(32.9)	3,435(5.9)	1,330(2.3)	58,504(100.0)	26,921(46.0)	6,388(10.9)	1,237(2.1)	1,801(3.1)	3,903(6.7)	6,370(10.9)	0(0.0)
Another doctor	30,569(73.6)	12,029(29.0)	8,439(20.3)	6,976(16.8)	14,501(34.9)	3,003(7.2)	900(2.2)	26,921(64.8)	41,539(100.0)	4,391(10.6)	875(2.1)	1,192(2.9)	2,813(6.8)	3,827(9.2)	0(0.0)
Physiotherapist / chiropractor	9,476(76.1)	4,139(33.2)	3,263(26.2)	3,677(29.5)	5,433(43.6)	1,265(10.2)	234(1.9)	6,388(51.3)	4,391(35.3)	12,456(100.0)	363(2.9)	429(3.4)	2,100(16.9)	887(7.1)	0(0.0)
Home help/ district nurse	1,294(49.6)	1,021(39.1)	416(15.9)	291(11.1)	836(32.0)	266(10.2)	133(5.1)	1,237(47.4)	875(33.5)	363(13.9)	2,611(100.0)	212(8.1)	144(5.5)	307(11.8)	0(0.0)
Pharmacy staff	2,503(66.7)	894(23.8)	930(24.8)	760(20.2)	1,396(37.2)	284(7.6)	73(1.9)	1,801(48.0)	1,192(31.8)	429(11.4)	212(5.6)	3,754(100.0)	514(13.7)	400(10.7)	0(0.0)
Alternative therapist	6,588(69.7)	2,277(24.1)	2,437(25.8)	2,406(25.4)	4,376(46.3)	733(7.8)	152(1.6)	3,903(41.3)	2,813(29.8)	2,100(22.2)	144(1.5)	514(5.4)	9,455(100.0)	1,163(12.3)	0(0.0)
None personal relation	0(0.0)	0(0.0)	0(0.0)	0(0.0)	0(0.0)	0(0.0)	0(0.0)	6,370(8.1)	3,827(4.9)	887(1.1)	307(0.4)	400(0.5)	1,163(1.5)	78,214(100.0)	67,774(86.7)
None prof. relation	85,250(49.5)	10,183(5.9)	12,598(7.3)	13,632(7.9)	22,682(13.2)	1,674(1.0)	1,370(0.8)	0(0.0)	0(0.0)	0(0.0)	0(0.0)	0(0.0)	0(0.0)	67,774(39.4)	172,148(100.0)

Patterns for each possible relation must be read horizontal e.g. all pattern involving *spouse/partner* (146,745; 100%) are combined with children in 15.2% of the symptom experiences, etc.

Each relation the diagonal across the matrix sum up to 100%.

Bold, black = cutoff ≥50%

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STROBE 2007 (v4) checklist of items to be included in reports of observational studies in epidemiology*
Checklist for cohort, case-control, and cross-sectional studies (combined)

Section/Topic	Item #	Recommendation	Reported on page #
Title and abstract	1	(a) Indicate the study's design with a commonly used term in the title or the abstract	1-2
		(b) Provide in the abstract an informative and balanced summary of what was done and what was found	2
Introduction			
Background/rationale	2	Explain the scientific background and rationale for the investigation being reported	4-5
Objectives	3	State specific objectives, including any pre-specified hypotheses	4-5
Methods			
Study design	4	Present key elements of study design early in the paper	5
Setting	5	Describe the setting, locations, and relevant dates, including periods of recruitment, exposure, follow-up, and data collection	5
Participants	6	(a) <i>Cohort study</i> —Give the eligibility criteria, and the sources and methods of selection of participants. Describe methods of follow-up <i>Case-control study</i> —Give the eligibility criteria, and the sources and methods of case ascertainment and control selection. Give the rationale for the choice of cases and controls <i>Cross-sectional study</i> —Give the eligibility criteria, and the sources and methods of selection of participants	5
		(b) <i>Cohort study</i> —For matched studies, give matching criteria and number of exposed and unexposed <i>Case-control study</i> —For matched studies, give matching criteria and the number of controls per case	-
Variables	7	Clearly define all outcomes, exposures, predictors, potential confounders, and effect modifiers. Give diagnostic criteria, if applicable	6-7
Data sources/ measurement	8*	For each variable of interest, give sources of data and details of methods of assessment (measurement). Describe comparability of assessment methods if there is more than one group	6,7,8
Bias	9	Describe any efforts to address potential sources of bias	16, 17, 18
Study size	10	Explain how the study size was arrived at	8-9
Quantitative variables	11	Explain how quantitative variables were handled in the analyses. If applicable, describe which groupings were chosen and why	6-7
Statistical methods	12	(a) Describe all statistical methods, including those used to control for confounding	7-8
		(b) Describe any methods used to examine subgroups and interactions	7-8
		(c) Explain how missing data were addressed	-
		(d) <i>Cohort study</i> —If applicable, explain how loss to follow-up was addressed <i>Case-control study</i> —If applicable, explain how matching of cases and controls was addressed	-

		<i>Cross-sectional study</i> —If applicable, describe analytical methods taking account of sampling strategy	
		(e) Describe any sensitivity analyses	-
Results			
Participants	13*	(a) Report numbers of individuals at each stage of study—eg numbers potentially eligible, examined for eligibility, confirmed eligible, included in the study, completing follow-up, and analysed	8-9
		(b) Give reasons for non-participation at each stage	8-9
		(c) Consider use of a flow diagram	8-9
Descriptive data	14*	(a) Give characteristics of study participants (eg demographic, clinical, social) and information on exposures and potential confounders	8
		(b) Indicate number of participants with missing data for each variable of interest	8
		(c) <i>Cohort study</i> —Summarise follow-up time (eg, average and total amount)	-
Outcome data	15*	<i>Cohort study</i> —Report numbers of outcome events or summary measures over time	-
		<i>Case-control study</i> —Report numbers in each exposure category, or summary measures of exposure	-
		<i>Cross-sectional study</i> —Report numbers of outcome events or summary measures	Table 1
Main results	16	(a) Give unadjusted estimates and, if applicable, confounder-adjusted estimates and their precision (eg, 95% confidence interval). Make clear which confounders were adjusted for and why they were included	-
		(b) Report category boundaries when continuous variables were categorized	-
		(c) If relevant, consider translating estimates of relative risk into absolute risk for a meaningful time period	-
Other analyses	17	Report other analyses done—eg analyses of subgroups and interactions, and sensitivity analyses	-
Discussion			
Key results	18	Summarise key results with reference to study objectives	17
Limitations	19	Discuss limitations of the study, taking into account sources of potential bias or imprecision. Discuss both direction and magnitude of any potential bias	17, 18, 19
Interpretation	20	Give a cautious overall interpretation of results considering objectives, limitations, multiplicity of analyses, results from similar studies, and other relevant evidence	19, 20, 21
Generalisability	21	Discuss the generalisability (external validity) of the study results	21
Other information			
Funding	22	Give the source of funding and the role of the funders for the present study and, if applicable, for the original study on which the present article is based	21

*Give information separately for cases and controls in case-control studies and, if applicable, for exposed and unexposed groups in cohort and cross-sectional studies.

Note: An Explanation and Elaboration article discusses each checklist item and gives methodological background and published examples of transparent reporting. The STROBE checklist is best used in conjunction with this article (freely available on the Web sites of PLoS Medicine at <http://www.plosmedicine.org/>, Annals of Internal Medicine at <http://www.annals.org/>, and Epidemiology at <http://www.epidem.com/>). Information on the STROBE Initiative is available at www.strobe-statement.org.

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The activation of professional and personal network relations when experiencing a symptom: A population-based cross-sectional study

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The activation of professional and personal network relations when experiencing a symptom:

A population-based cross-sectional study

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ABSTRACT

Objective(s): To describe patterns of disclosure of symptoms experienced among people in the general population to persons in their personal and/or professional network.

Design: A population-based cross-sectional study. Data was collected from a web-based survey.

Setting: The general population in Denmark

Participants: 100,000 individuals randomly selected, representative of the adult Danish population aged ≥ 20 years were invited. Approximately 5% were not eligible for inclusion. 49,706 (men = 23,240; women = 26,466) of 95,253 eligible individuals completed the questionnaire; yielding a response rate of 52.2%. Individuals completing all questions regarding social network relations form the study base (n=44,313).

Primary and secondary outcome measures: Activation of personal and/or professional relations when experiencing a symptom.

Results: The 44,313 individuals reported in total 260,079 symptom experiences within the last four weeks. No professional network relation was used in two thirds of all reported symptoms. The GP was the most frequently reported professional relation activated (22.5%). People reporting to have available personal relations were slightly less inclined to contact the GP (21.9%) when experiencing a symptom compared to people with no reported personal relations (26.8%). The most commonly activated personal relations were *spouse/partner* (56.4%) and *friend* (19.6%). More than a quarter of all reported symptom experiences was not shared with anyone, personal nor professional. The symptom experiences with the lowest frequency of network activation were symptoms such as black stool, constipation, change in stool texture and frequent urination.

Conclusion: This study emphasises variation in the activation of network relations when experiencing a symptom. Symptoms were shared with both personal and professional relations, but different patterns of disclosures were discovered. For symptoms derived from the urogenital or colorectal region, the use of both personal and professional relations was relatively small, which might indicate reticence to involve other people when experiencing symptoms of that nature.

Keywords: Signs and symptoms, Social network, Help-seeking behaviour, Primary health care

STRENGTHS AND LIMITATIONS OF THIS STUDY

- This study was based on data from a large cross-sectional nationwide population-based study, inviting 100,000 randomly selected Danish people in the age group 20 to 107 years.
- .
- Data was based on individuals who had reported actual experiences of symptoms, thus reflecting true actions rather than hypothetical considerations.
- Telephone interviews offered to participants without opportunity to complete the online survey enabled additional responses from individuals aged 80 years or above, who are usually rarely represented in surveys.
- Based on data extracted from the questionnaire, it was not possible to obtain information on the quality or content of the dialogues between the respondents and their relations. We can solely describe whether a relation was activated or not.

INTRODUCTION

The epidemiology of symptom experiences, and what is often referred to as the symptom iceberg, referring to the observation that only a minor proportion of all experienced symptoms are shared with a general practitioner, had its breeding ground in the study by Last in the 1960s[1]. Last illustrated that diseases presented to GPs only represent the tip of the iceberg and thus hypothesized that the majority of symptom experiences are managed in a private setting[2]. Contemporary studies also suggest that the majority of symptoms experienced in the general population are not presented to the GP or other healthcare-providers and remain below the so-called 'water line'[3-5]. Elliot et al. for example describes that only 12% of symptoms led to a consultation with a primary health professional[3].

Symptom iceberg studies are of relevance because they provide insights into the prevalence of symptom experiences and the social organisation of symptom management. Traditional symptom iceberg studies, however, primarily explored changes of 'the water line' and asked the binary question: did you seek health care or not. We, thus have only sparse information on the variety of social encounters individuals engage in when experiencing symptoms, and whether it is possible to identify social patterns of network activation that are relevant to understanding how or when people contact the GP. This is of relevance as some research suggests that disclosure of symptoms might affect the timing of the healthcare seeking. A review of factors associated with healthcare seeking for symptoms indicative of serious diseases, such as cancer, has identified a number of triggers; demographic factors (e.g. age, gender), psychological factors (e.g. concern, fear), behavioural factors (e.g. self-medication, watchful waiting) and social relations (e.g. influence of family and friends) [6, 7]. In particular, disclosure of a symptom to a family member or friend has been identified as a trigger in favour of seeking medical help for potentially alarming symptoms [8, 9].

Recounting of symptoms to a family member or friend can, however, either prompt or demotivate individuals in the decision to seek medical help, especially within socioeconomic groups and categories of symptoms [5].

In adding to this binary-focused research on symptom experiences and healthcare seeking, sociologist Pescosolido and colleagues conducted studies exploring patterns of social network activation in relation to

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3 illness episodes[10]. In this approach, contacting the GP with a symptom experienced is not an 'either/or'
4 but potentially part of a larger social pattern. Overall, they showed that there appears to be a limited
5 repertoire of patterns which are affected by the social setting and medical incidents, which in turn influence
6 the network opportunities. Inspired by Pescosolido and colleagues' work on social network activation[10],
7 the objective of this study is to describe patterns of disclosure of symptoms experienced among people in
8 the general population to persons in the personal and/or professional network in the context of the Danish
9 welfare state.
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20 **METHOD**

21 **Study design**

22 This Danish nationwide cross-sectional study comprising a random sample of 100,000 people, representative
23 of the adult Danish population aged 20 years or above, uses data from the Danish Symptom Cohort, which
24 has been described previously[11, 12]. Baseline data presented in this paper were collected in a web-based
25 survey. The data collection was conducted from June to December 2012.
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33 **Subjects and sampling**

34 All Danish citizens are registered with a unique personal identification number in the Danish Civil
35 Registration System (CRS), which contains information on any Danish resident's date of birth, gender,
36 migration, etc. [13]. The sample for this study was randomly selected using the CRS and was invited to
37 participate in the survey. Each individual received a postal letter explaining the purpose of the study. In the
38 letter, a unique 12-digit login to a secure webpage was included. This provided access to a comprehensive
39 web-based questionnaire. In order to prevent the exclusion of people with no access to a computer, a tablet
40 or a smartphone, the participants were offered the opportunity to respond to the survey in a telephone
41 interview [11].
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Questionnaire

The overall concept of the questionnaire was to measure the prevalence of self-reported symptom experiences in the general population and explore dimensions related to activation of social networks and healthcare seeking decisions.

In order to explore the prevalence of different symptom experiences, 44 different predefined symptom categories were included based on a review of literature, and national and international cancer referral guidelines (4-6). In addition, unspecific general symptoms which often are presented to the GP, e.g. back pain, headache and tiredness, were included.

The questionnaire was pilot- and field-tested and adjusted accordingly. The methodological framework for developing the questionnaire is described in details elsewhere[11].

Items regarding each of the included symptom categories were phrased: "Have you experienced any of the following bodily sensations, symptoms or discomforts within the past four weeks?" For each symptom experience reported, respondents were asked whom they talked to, if anyone concerning the symptom. Two dimensions of social network relations were explored, a professional and a personal dimension, respectively.

The first item concerning the professional dimension was phrased: "Have you contacted your general practitioner with the symptom or discomfort, in person, by phone or by e-mail?" Afterwards respondents were asked: "Which of the following other healthcare professionals or therapists have you talked to regarding the symptoms or discomforts (through appointment, by telephone or by email)? The following healthcare professionals were selectable: *Another doctor* (practicing specialist, out-of-hours physician or hospital physician), *physiotherapist/chiropractor*, *home help/district nurse*, *pharmacy staff*, *alternative therapist* (e.g. homeopath, healer, reflexologist), *none* and *another* category. The items concerning the personal relations were phrased: "Which of the following members of your family or social network have you talked to about the symptoms or discomforts? The personal relations selectable were *spouse/partner*, *children*, *parents*, *colleague /classmate*, *friend*, *neighbour*, *siblings*, *none* and *another* category. More than one of the relations could be ticked off.

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3 In order to qualify the identification of the personal and professional relations activated when experiencing a
4 symptom, we found it relevant to estimate aspects of social network relations, i.e. whether the respondents
5 had available personal relations or accessibility to other people. For this purpose, the following four items
6 were constructed: 1. "How often are you in contact with friends, acquaintances or family that you do not live
7 with? Contact indicates that you are together, talking with each other on the phone, writing to each other
8 etc." (daily or almost daily / once or twice a week / once or several times a month / less than once a month /
9 Never / I don't know). 2. "If you become ill and need help with practical things, can you count on help from
10 others? (Others means people you do not live with)" (Yes, definitely / Yes, maybe /No). 3. "Does it ever
11 happen that you are alone, even if you want to be in the company of others?" (Yes, often / Yes, once in a
12 while / Yes, but rarely / No, never or almost never). 4. "Do you have someone to talk to if you have problems
13 or need support?" (Yes, often / Yes, mostly / Yes, sometimes / No, never or almost never).

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27 On the basis of these four items, individuals were categorised as having an 'available relation' if the following
28 responses were chosen: Often in contact with others (daily or almost daily/ once or twice a week/ once or
29 several times a month), Having available persons who can help (Yes, definitely / Yes, maybe), being alone
30 when desiring to be with others (Never or almost never/ rarely/ once in a while) and having a person to talk
31 to in case of problems (often/ mostly/ sometimes).

32 33 34 35 36 37 38 **Data analysis**

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The data set used in the analyses was constructed by merging all reported symptoms experienced by the
respondents with each individual symptom experience used as study case.

Basic descriptive analyses were used to study the activation of each personal and professional relation when
experiencing a symptom. Activation is somewhat agent-neutral in the sense that the data does not allow for
insight into who approached who. This is of particular relevance in respect to the personal relations.

To explore common patterns of relations used when experiencing a symptom, cluster analysis was
performed. These analyses were repeated for the subgroup of people who were categorised as having
available personal relations or accessibility to other people.

Prevalences of various combinations of two relations activated when experiencing a symptom were

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3 calculated and displayed in an expanded two times two table. Proportions were calculated as percentages
4 (%) , based on the binominal distribution. For each relation, the diagonal across the matrix sums up to 100%.
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7 In order to estimate the proportion of the 44 different symptom experiences with regard to the possible
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9 network relations, three categories of relations were defined; *professional relations*, *personal relations* and
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11 *Neither use of personal nor professional*, respectively. Proportions were calculated as percentages (%), based
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13 on the binominal distribution.
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16 All data analyses were conducted using STATA statistical software 14.1 (StataCorp, College Station, TX, USA).
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20 RESULTS

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22 Of the 100,000 randomly selected individuals, 4,474 (4.7%) were not eligible for inclusion. Of the 95,253
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24 (95.3%) eligible subjects, 49,706 individuals completed the questionnaire, yielding a response rate of 52.2%.
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26 Some 1,208 (2.4%) completed the questionnaire by telephone interview (Figure 1). The respondents were
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28 fairly representative of the study sample and thus representative of the Danish population according to
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30 ethnicity, socioeconomic and demographic variables. However, slightly more respondents were females,
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32 married/living together, had a high educational and income level and were attached to the labour market
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34 [12].
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3 **FIGURE 1:** Study sample
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9 **Personal and professional relations activated when experiencing a symptom**

10 A total of 44,313 individuals answered all the relevant items with regard to activation of social network
11 relations and form the basis for this study, Figure 1. They reported a total of 260,079 symptoms (Table 1).
12
13 For 78,214 (30.1%) of all symptom experiences, no personal relation was activated. The most commonly
14 activated personal relation was *spouse/partner*, who was activated in 56.4% of the symptom experiences,
15 followed by *friends* (19.6%). No professional network relation was activated in 172,148 (66.2%) of the
16 symptom experiences. The most frequently reported professional relation was the *GP*, who was contacted
17 for 22.5% of the symptom experiences (Table 1).
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TABLE 1. Descriptive overview of study sample with regard to symptom experiences and reported relations.

	Study sample		Number of symptoms	
	N	(%)	n	(%)
Study sample				
<i>Overall</i>	44,313	(100.0)	260,079	(100.0)
Gender				
<i>Men</i>	20,546	(46.4)	107,192	(41.2)
<i>Women</i>	23,767	(53.6)	152,887	(58.7)
Age				
<i>20-39</i>	11,262	(25.4)	77,870	(29.9)
<i>40-59</i>	18,224	(41.1)	106,195	(40.8)
<i>60-79</i>	13,641	(30.8)	68,806	(26.5)
<i>80+</i>	1,186	(2.7)	7,208	(2.8)
Personal relation				
<i>Spouse/partner</i>			146,745	(56.4)
<i>Children</i>			31,177	(12.0)
<i>Parents</i>			29,290	(11.3)
<i>Colleague/classmate</i>			28,335	(10.9)
<i>Friend</i>			51,065	(19.6)
<i>Neighbour</i>			6,537	(2.5)
<i>Sibling</i>			3,279	(1.3)
<i>None</i>			78,214	(30.1)
<i>Other</i>			2,692	(1.0)
Professional relation				
<i>General practitioner</i>			58,504	(22.5)
<i>Another doctor</i>			41,539	(16.0)
<i>Physiotherapist/chiropractor</i>			12,456	(4.8)
<i>Home help/district nurse</i>			2,611	(1.0)
<i>Pharmacy staff</i>			3,754	(1.4)
<i>Alternative therapist</i>			9,455	(3.6)
<i>None</i>			172,148	(66.2)
<i>Other</i>			6,927	(2.7)

Patterns of network activation

When merging all relations into one source of network including both professional and personal relations, nearly 3,000 different patterns of relations occurred for the 260,079 symptoms reported. The twenty most commonly activated patterns of relations are listed in Table 2. The most prevalent pattern was the activation of no relations. More than a quarter (26.1%) of all reported symptom experiences was not shared with anyone; neither personal nor professional. Disclosure of symptoms to one's *spouse/partner* was almost consistently throughout the first ten patterns, standing alone or in combination with either a professional

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3 relation or another personal relation. Involving both personal and professional relations by activating a
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5 *spouse/partner* and the *GP* was the third most common pattern of network relations (Table 2).

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7 Even though 2,975 patterns occurred, two-thirds of all symptom experiences were represented in the first
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9 ten patterns of relations. This contributes to a limited repertoire of patterns of relations, most of them
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11 pluralistic and some single (Table 2).

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13 For the subgroup of respondents who reported an available network of relations, small differences were
14
15 seen in the patterns of relations compared to those of the full sample. A tendency towards higher activation
16
17 of personal relations and less activation of both the *GP* and *other doctors* was seen in this group.

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19 Furthermore, this group was less inclined to contact the *GP* (21.9%) when experiencing a symptom
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21 compared to people without an available network of relations or accessibility to other people (26.8%) (Table
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Table 2. The most frequent patterns of relations reported with regard to a symptom experience.

Patterns of relations	Full sample (n=260,079)		Subgroup with available relations* (n=226,013)	
	n (%)	Rank	n (%)	Rank ¹
None	67,774 (26.1)	1	57,625 (25.4)	1
Spouse/partner	61,050 (23.5)	2	55,307 (24.4)	2
Spouse/partner + GP	8,773 (3.4)	3	7,763 (3.4)	3
Spouse/partner + GP + Another doctor	7,188 (2.8)	4	6,110 (2.7)	4
Friend	6,270 (2.4)	5	5,463 (2.4)	5
Spouse/partner + Friend	4,877 (1.9)	6	4,524 (2.0)	6
Spouse/partner + Another doctor	4,479 (1.7)	7	3,876 (1.7)	7
GP	3,898 (1.5)	8	2,885 (1.3)	10
Spouse/partner + Colleague	3,601 (1.4)	9	3,360 (1.5)	8
Spouse/partner + Children	3,504 (1.4)	10	3,183 (1.4)	9
Spouse/partner + Parent	2,816 (1.1)	11	2,567 (1.1)	11
Parent	2,630 (0.7)	12	2,171 (1.0)	12
Colleague	1,931 (0.7)	13	1,679 (0.7)	13
Spouse/partner + Children + GP + Another doctor	1,845 (0.7)	14	1,614 (0.7)	15
Children	1,839 (0.7)	15	1,440 (0.6)	16
Spouse/partner + Colleague + Friend	1,775 (0.7)	16	1,675 (0.7)	14
Another doctor + GP	1,693 (0.7)	17	1,226 (0.5)	21
Another doctor	1,660 (0.6)	18	1,280 (0.6)	18
Spouse/partner + Parent + Friend	1,410 (0.5)	19	1,311 (0.6)	17
Spouse/partner + Children + GP	1,397 (0.5)	20	1,241 (0.5)	20
Spouse/partner + Physiotherapist/chiropractor	1,382 (0.5)	21	1,264 (0.6)	19

*Respondents reporting available personal relations or accessibility to other people.

¹ Rank according to the sub-analysis with respondents who have reported available personal relations or accessibility to other people.

Density of patterns

The figures highlighted in bold in Table 3 represent patterns with high densities across each cluster of two relations using an arbitrary cut-off at 50% level [10]. For each relation, the diagonal across the matrix sums up to 100%. The main collaborator in the patterns comprising the *GP* was the *spouse/partner* (70.9%). This means that when the *GP* is contacted with regard to a symptom experience, the *spouse/partner* is involved in 70.9% of the cases. Conversely, when the *spouse/partner* was activated with regard to a symptom experience, the *GP* was only involved in less than one third of the cases (28.3 %). Across all possible relations listed in Table 3, the *spouse/partner* was one of the main relations to be activated when experiencing a symptom. When a more distant personal relation such as a *neighbour* or *colleague* was activated, it was often in combination with various different relations. This is opposite to the patterns

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3 including a *spouse/partner*, who was often activated as a single relation or in combination with limited close
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5 relations. When a professional relation was activated, it was often in combination with a *GP*. Looking at the
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7 patterns comprising *none personal relation* the most activated relation was the *GP* (8.1%) (Table 3).
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TABLE 3: Density for patterns of both professional and personal relation (n(%)). Enhanced two times two table with all relations included.

Relations	Spouse/partner	Children	Parents	Colleague/ classmate	Friend	Neighbour	Sibling	General practitioner	Another doctor	Physiotherapist / chiropractor	Home help/ district nurse	Pharmacy staff	Alternative therapist	None personal relation	None prof. relation
Spouse/partner	146,745(100.0)	22,254(15.2)	19,109(13.0)	20,489(14.0)	30,548(20.8)	4,475(3.0)	1,395(1.0)	41,479(28.3)	30,569(20.8)	9,476(6.5)	1,294(0.9)	2,503(1.7)	6,588(4.5)	0(0.0)	85,250(58.1)
Children	22,254(71.4)	31,177(100.0)	5,744(18.4)	7,383(23.7)	12,971(41.6)	3,635(11.7)	622(2.0)	15,319(49.1)	12,029(38.6)	4,139(13.3)	1,021(3.3)	894(2.9)	2,277(7.3)	0(0.0)	10,183(32.7)
Parents	19,109(65.2)	5,744(19.6)	29,290(100.0)	9,953(34.0)	15,712(53.6)	2,081(7.1)	758(2.6)	11,339(38.7)	8,439(28.8)	3,263(11.1)	416(1.4)	930(3.2)	2,437(8.3)	0(0.0)	12,598(43.0)
Colleague/ classmate	20,489(72.3)	7,383(26.1)	9,953(35.1)	28,335(100.0)	15,720(55.5)	2,653(9.4)	563(2.0)	9,817(34.6)	6,976(24.6)	3,677(13.0)	291(1.0)	760(2.7)	2,406(8.5)	0(0.0)	13,632(48.1)
Friend	30,548(59.8)	12,971(25.4)	15,712(30.8)	15,720(30.8)	51,065(100.0)	4,627(9.1)	1,222(2.4)	19,258(37.7)	14,501(28.4)	5,433(10.6)	836(1.6)	1,396(2.7)	4,376(8.6)	0(0.0)	22,682(44.4)
Neighbour	4,475(68.5)	3,635(55.6)	2,081(31.8)	2,653(40.6)	4,627(70.8)	6,537(100.0)	158(2.4)	3,435(52.5)	3,003(45.9)	1,265(19.4)	266(4.1)	284(4.3)	733(11.2)	0(0.0)	1,674(25.6)
Sibling	1,395(42.5)	622(19.0)	758(23.1)	563(17.2)	1,222(37.3)	158(4.8)	3,279(100.0)	1,330(40.6)	900(27.4)	234(7.1)	133(4.1)	73(2.2)	152(4.6)	0(0.0)	1,370(41.8)
General practitioner	41,479(70.9)	15,319(26.2)	11,339(19.4)	9,817(16.8)	19,258(32.9)	3,435(5.9)	1,330(2.3)	58,504(100.0)	26,921(46.0)	6,388(10.9)	1,237(2.1)	1,801(3.1)	3,903(6.7)	6,370(10.9)	0(0.0)
Another doctor	30,569(73.6)	12,029(29.0)	8,439(20.3)	6,976(16.8)	14,501(34.9)	3,003(7.2)	900(2.2)	26,921(64.8)	41,539(100.0)	4,391(10.6)	875(2.1)	1,192(2.9)	2,813(6.8)	3,827(9.2)	0(0.0)
Physiotherapist/ chiropractor	9,476(76.1)	4,139(33.2)	3,263(26.2)	3,677(29.5)	5,433(43.6)	1,265(10.2)	234(1.9)	6,388(51.3)	4,391(35.3)	12,456(100.0)	363(2.9)	429(3.4)	2,100(16.9)	887(7.1)	0(0.0)
Home help/ district nurse	1,294(49.6)	1,021(39.1)	416(15.9)	291(11.1)	836(32.0)	266(10.2)	133(5.1)	1,237(47.4)	875(33.5)	363(13.9)	2,611(100.0)	212(8.1)	144(5.5)	307(11.8)	0(0.0)
Pharmacy staff	2,503(66.7)	894(23.8)	930(24.8)	760(20.2)	1,396(37.2)	284(7.6)	73(1.9)	1,801(48.0)	1,192(31.8)	429(11.4)	212(5.6)	3,754(100.0)	514(13.7)	400(10.7)	0(0.0)
Alternative therapist	6,588(69.7)	2,277(24.1)	2,437(25.8)	2,406(25.4)	4,376(46.3)	733(7.8)	152(1.6)	3,903(41.3)	2,813(29.8)	2,100(22.2)	144(1.5)	514(5.4)	9,455(100.0)	1,163(12.3)	0(0.0)
None personal relation	0(0.0)	0(0.0)	0(0.0)	0(0.0)	0(0.0)	0(0.0)	0(0.0)	6,370(8.1)	3,827(4.9)	887(1.1)	307(0.4)	400(0.5)	1,163(1.5)	78,214(100.0)	67,774(86.7)
None prof. relation	85,250(49.5)	10,183(5.9)	12,598(7.3)	13,632(7.9)	22,682(13.2)	1,674(1.0)	1,370(0.8)	0(0.0)	0(0.0)	0(0.0)	0(0.0)	0(0.0)	0(0.0)	67,774(39.4)	172,148(100.0)

Patterns for each possible relation must be read horizontal, e.g. all pattern involving spouse/partner (146,745; 100%) are combined with children in 15.2% of the symptom experiences, etc.

For each relation the diagonal across the matrix sum up to 100%.

Bold, black = cutoff $\geq 50\%$

Type of symptom and network activation

The symptoms with the highest proportion of activation of neither personal nor professional relations were symptoms such as *black stool*, *constipation* and *change in stool texture*. The proportion of activating a professional relation was highest for *blood in urine*, *shortness of breath* and *back pain*. Personal relations were most often used when experiencing *back pain*, *repeated vomiting*, *feeling unwell* and *tiredness*. *Back pain* was the symptom which overall activated most relations, as only 8.8% of all experienced *back pains* were kept to oneself (Table 4).

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Table 4: The proportion of contacts to professional, personal and “use of neither personal nor professional” relation with regard to the 44 different symptom experiences. The total number of symptom experiences was 260,079.

Type of symptom	Number of symptoms N	Use of professional relations n (%)	Use of personal relations n (%)	Use of neither personal nor professional n (%)
Tiredness	23,880	8,040 (33.7)	19,505 (81.7)	3,890 (16.3)
Night-time urination	23,337	4,565 (19.6)	14,266 (61.1)	8,456 (36.2)
Lack of energy	17,952	5,878 (32.7)	14,026 (78.1)	3,460 (19.3)
Headache	17,564	6,438 (36.6)	13,135 (74.8)	3,900 (22.2)
Back pain	15,474	10,809 (69.8)	13,478 (87.1)	1,363 (8.8)
Abdominal bloating	14,238	3,627 (25.5)	9,074 (63.7)	4,687 (32.9)
Memory problems	9,480	3,010 (31.7)	7,345 (77.5)	1,903 (20.1)
Abdominal pain	9,365	4,150 (44.3)	7,434 (79.4)	1,627 (17.4)
Coughing	8,535	2,899 (33.9)	5,579 (65.4)	2,575 (30.2)
Concentration problems	8,728	2,972 (34.1)	5,817 (69.6)	2,240 (26.8)
Change in stool texture	8,207	2,216 (27.0)	4,049 (49.3)	3,662 (44.6)
Dizziness	7,604	3,570 (46.9)	5,687 (74.8)	1,592 (20.9)
Feeling unwell	7,160	2,814 (39.3)	5,954 (83.2)	984 (13.7)
Constipation	6,980	1,885 (27.0)	3,251 (46.6)	3,279 (47.0)
Increase in waist circumference	6,308	1,385 (22.0)	4,195 (66.5)	1,928 (30.6)
Change in stool frequency	6,199	1,654 (26.7)	3,232 (52.1)	2,632 (42.5)
Diarrhoea	6,184	1,730 (28.0)	3,401 (55.0)	2,469 (39.9)
Nausea	6,007	2,098 (34.9)	4,559 (75.9)	1,248 (20.8)
Swollen legs	5,850	3,154 (53.9)	4,342 (74.2)	1,112 (19.0)
Difficulty in emptying the bladder	5,546	2,106 (38.0)	2,935 (52.9)	2,143 (38.6)
Frequent urination	5,024	1,836 (36.5)	3,108 (61.9)	1,616 (32.2)
Stress incontinence	4,658	1,352 (29.0)	2,633 (56.5)	1,765 (37.9)
Erectile dysfunction*	4,161	1,743 (41.8)	3,030 (72.8)	909 (21.8)
Pelvic pain*	3,848	1,505 (39.1)	2,595 (67.4)	1,081 (28.1)
Shortness of breath	3,789	2,520 (66.5)	2,994 (79.0)	537 (14.2)
Hoarseness	3,654	1,036 (28.3)	2,227 (60.9)	1,264 (34.6)
Urge incontinence	2,952	1,118 (37.9)	1,861 (63.0)	897 (30.4)
Loss of appetite	2,949	902 (30.6)	1,900 (64.4)	922 (31.3)
Blood in stool/rectal bleeding	2,191	1,002 (45.7)	1,267 (57.8)	744 (34.0)
Pelvic pain during intercourse*	2,037	784 (38.5)	1,609 (79.0)	359 (17.6)
Fever	1,905	642 (33.7)	1,507 (79.1)	324 (17.0)
Difficulty swallowing	1,645	818 (49.7)	1,215 (73.9)	340 (20.7)
Weight loss	1,407	520 (37.0)	1,044 (74.2)	314 (22.3)
Incontinence without stress/urge	1,102	547 (49.6)	654 (59.3)	332 (30.1)
Pain/burning when urinating	997	594 (59.6)	654 (65.6)	243 (24.4)
Lump/swollen lymph nodes	784	413 (52.7)	543 (69.3)	185 (23.6)
Black stool	740	194 (26.2)	246 (33.2)	429 (58.0)
Vaginal bleeding after intercourse*	600	258 (47.5)	456 (76.0)	110 (18.3)
Repeated vomiting	600	300 (50.0)	502 (83.7)	75 (12.5)
Postmenopausal bleeding*	342	156 (45.6)	217 (63.5)	99 (28.9)
Blood in urine	272	233 (85.7)	217 (79.8)	27 (9.9)
Blood in semen*	90	57 (63.3)	51 (56.7)	27 (30.0)
Coughing up blood	59	35 (59.3)	41 (69.5)	13 (22.0)
Blood in vomit	43	20 (46.5)	30 (69.8)	12 (27.9)

*Gender specific symptoms.

DISCUSSION

Article summary

Symptoms are shared with both the personal and the professional network, but different patterns of disclosures were discovered. More than a quarter of all reported symptom experiences were not shared with anyone; personal nor professional. Whether individuals had an available network or not, the *GP* was the most frequently reported professional relation activated, although people reporting available network relations were slightly less inclined to contact their *GP*. Across all possible relations, the *spouse/partner* was the main relation to be activated when experiencing a symptom and involved in the majority of symptoms also shared with the *GP*.

The study also emphasises variation in disclosure of different symptoms. For symptoms derived from the urogenital or colorectal region, the use of both personal and professional relations was relatively small, which might indicate reticence to involve other people when experiencing symptoms that might be subject to stigmatization, embarrassment or shame.

Strengths and limitations

This study was a large cross-sectional nationwide population-based study, inviting 100,000 people randomly selected from the Danish CRS register, representative of the adult Danish population aged 20 years or above. To our knowledge, such a large-scale nationwide population-based study, investigating a wide range of self-reported symptom experiences and dimensions related to network activation, has not previously been conducted.

The response rate of 52.2% was comparable or even higher as compared to previous surveys measuring symptom prevalence in the general population [3, 14]. Although a preponderance of the respondents were women, and the respondents were slightly older than the non-respondents, the respondents were fairly representative of the general Danish population. However, differences between the respondents and the

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3 non-respondents regarding other parameters, which might include a risk of over- or underestimating the
4 proportion of *GP* contacts, cannot be eliminated. For more details, see Elnegaard et al.[12].
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8 To avoid a possible selection bias due to the web-based design of the questionnaire, participants without
9 access to a computer, a smartphone or a tablet were offered the possibility of conducting the survey as a
10 telephone interview. These interviews enabled additional responses from the oldest individuals, aged 80
11 years or above, who usually are rarely represented in surveys.
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15 The participants were asked to recall symptom experiences within the preceding four weeks and whether
16 they had contacted a personal or professional relation with these symptoms at any time. Recall bias cannot
17 be completely eliminated in questionnaire studies [15]. Some may misplace older symptom experiences in
18 the specified timeframe due to the severity of symptoms, or because they had contacted a GP about them
19 [16]. Others may have forgotten about a symptom experience or a GP contact, because the symptom turned
20 out to be nothing to worry about or simply due to memory decay [17]. The recall period of four weeks was
21 chosen to ensure enough symptom experiences to obtain statistically precise estimates, even for rare
22 symptoms, while still assuming that individuals could recall symptoms and whom they talked to or contacted
23 fairly accurately [18, 19].
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27 The term symptom as presented in the discipline of biomedicine is influenced by a desire to predict
28 underlying diseases and risks of negative effects on health. From the biomedical perspective, it is common to
29 distinguish between subjective health complaints (symptoms) and signs with the latter being objectively
30 verifiable (e.g. blood in the urine or jaundice), whereas symptoms often refer to subjective complaints. The
31 WONCA Dictionary of General/Family Practice defines a symptom as “any subjective evidence of a health
32 problem as perceived by the patient”[20]. This definition implies that symptom experiences are not viewed
33 as objective, clinical phenomena, but are seen as the result of the patient’s own interpretation process, in
34 which bodily sensations or changes are transformed into signs of ill health [21-23]. Accordingly, we defined
35 subjectively reported symptom experiences as multidimensional constructions embedded in a complex
36 interplay of biological, psychological, and cultural factors, and interpreted the symptom experiences
37 reported in the survey as reflections of the individually experienced responses to bodily changes or
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3 sensations.

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5 There are certain limitations to using data extracted from a questionnaire-based survey; among others it
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7 does not allow insight into what kinds of bodily sensations are included or excluded by respondents as
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9 symptoms [23]. Following this line of reflection, the design and scope of the study was not designed to
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11 obtain data on the quality or content of the dialogues between the respondents and their network
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13 relation(s). Furthermore, the chronological order of the activation of relations was also not able to collected.
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15 We can solely describe whether a relation was activated or not.
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18 More response options to symptom experience could have been presented the respondents. Especially using
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20 the social media or the internet might have been a common response pattern to symptom experience
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22 among the young respondents. However, we chose the personal and professional network relations for
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24 simplicity in an already comprehensive questionnaire.
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27 The results presented in this paper are not static nor generic representations of symptom experience
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29 management. As repeatedly illustrated in anthropological literature on illness experiences and the
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31 management of the body in everyday life, the articulation and management of bodily sensations as
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33 symptoms unfold in the relationship between subjective experience and cultural indexations of sensations as
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35 symptoms [23], as well as existing norms and values that guide population-healthcare system interaction
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37 [24]. What this paper presents is a general 'epidemiology of bodily experience'. How many symptom
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39 experiences may be reported in the Danish population at a given moment in time, and how do people
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41 respond to those experiences. This kind of insight generates knowledge of symptom disclosures which is
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43 specific to cultures like Denmark and not necessarily generalisable to other people living in different
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45 cultures.
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48 49 50 **Comparison with existing literature**

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52 In the present study, more than one-fifth of the symptom experiences were shared with the *GP*. This result is
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54 lower compared to Pescosolido [10], who found that the *GP* was involved in 85.4% of the illness episodes
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56 registered in a retrospective survey. The high utilisation of the *GP* found in Pescosolido[10] was expected as
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3 the study selected episodes of illness on the basis of e.g. severity and recency. In contrast, the findings in the
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5 present study were derived from a random sample in an unselected population reporting symptom
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7 experiences. Furthermore, the present study was conducted in a gate-keeper-system with free access to the
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9 GP (i.e. including through email) [25] which could theoretically increase the use of the GP compared to the
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11 American health system described in Pescosolido[10].
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14 More than a fourth of the symptom experiences reported did not result in activation of neither a personal
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16 nor a professional relation. This finding was lower compared to a recent study performed (48.6%)[3], but
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18 generally consistent with studies conducted earlier [26-28]. Moreover, the overall proportion of GP
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20 activation was higher compared to similar studies conducted [3, 26, 27].
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23 Within the present study the most activated personal relation was the *spouse/partner*, who was involved in
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25 more than half of all the symptoms reported. The fact that the *spouse/partner* was activated when people
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27 experienced a symptom was not surprising, but an interesting aspect in the present study was the fact that
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29 only a quarter of all symptoms discussed with the *spouse/partner* was also presented to the GP, whereas the
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31 symptoms discussed with the GP had also been discussed with the *spouse/partner* in almost three-quarters
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33 of the symptom experiences. These findings could indicate that the personal relation can act as a trigger of
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35 healthcare seeking. Moreover, the results underline that many symptoms are still kept below the 'water-
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37 line' of the symptom iceberg.
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40 Various readings of these findings may be presented. It has been suggested that the social management of
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42 illness in welfare states is increasingly institutionalised and professionalised[29]. This would explain why
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44 people in our study, to a high degree, seek medical assistance when experiencing symptoms and perhaps
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46 also why people seem hesitant in activating personal networks. Overall, it may suggest a form of
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48 privatisation of the body, and the results are illustrative of how authority in the social management of illness
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50 is increasingly placed in the professional sector.
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54 Nearly 3,000 different patterns of activated relations with regard to a symptom experience were revealed in
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56 the present study, but the density within the first five patterns accounted for nearly 60% of all patterns. This
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3 was in line with Pescosolido[10], who concludes that there appears to be a limited repertoire of patterns of
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5 choice, most of them pluralistic and some single.

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7 Furthermore, Pescosolido [10] only found a few factors influencing which relations were activated when
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9 experiencing an illness episode. Those were social characteristics, which differentiated the strategies
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11 activated but not whether the GP was contacted. In the present study, people without an available personal
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13 network of relations more often activated the GP in comparison to people with a potential social network.
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15 Moreover, some of the variation found in the activation of network relations might be explained by a
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17 difference in the characteristics of the symptom and the symptom categories. The present study comprises
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19 44 quite diverse symptom categories in contrast to studies only comprised of a few alarming symptoms of
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21 cancer [30, 31]. We found a tendency of solitariness or a higher proportion of not activating a network
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23 relation with regard to symptoms originating from the urogenital or colorectal region. This corresponds to
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25 findings from the cancer literature, where change in bowel and bladder habits was associated with a longer
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27 patient interval [8] often due to embarrassment, fear or taboo[6].
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33 **IMPLICATIONS FOR RESEARCH AND PRACTICE**

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35 This study adds insights to the research on healthcare seeking and social network by exploring two
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37 dimensions of social variation in network activation and use of GP. Reasons for no activation of a network
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39 relation when experiencing a symptom can be that people either intentionally chose not to activate anyone
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41 in their social network, or that people have no access to a social network of relations. In this population-
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43 based setting, we found that more than a quarter of all reported symptom experiences were not shared with
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45 anyone, neither personal nor professional, regardless of accessibility to social network relations.
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49 The present study speaks in favour of that the social management of illness has been increasingly
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51 institutionalised, as people with sparse access to personal network relations made use of the GP to a greater
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53 extent, which additionally stresses the GPs role in general but particularly with regard to people lacking
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55 available social network relations.

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57 For symptoms related to the urogenital or colorectal region, the activation of either personal or professional
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3 relations was relatively low, which might indicate reticence to involve other people when experiencing
4 symptoms connected to these anatomical regions. Further research into the characteristics of potential
5 barriers to contacting the GP about a symptom related to these parts of the body would be useful in order to
6
7 reduce barriers of communication when contacting a GP.
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14
15 The study is financially supported by the Novo Nordisk Foundation and the Danish Cancer Society. The
16 funding sources had no involvement in the study or in the approval of the manuscript.
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19 20 21 **ETHICAL APPROVAL**

22
23 The Regional Scientific Ethics Committee for Southern Denmark evaluated the project and concluded that no
24 further approval was necessary due to Danish legislation. The participants in the study were clearly informed
25 that there would be no clinical follow-up, and that they should contact their own GP in case of concern or
26 worry. The project was approved by the Danish Data Protection Agency (Journal no. 2011-41-6651).
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30 31 32 **COMPETING INTEREST STATEMENT**

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34 The authors declare that they have no competing interests.
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38 39 **ACKNOWLEDGEMENTS**

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41 This survey is conducted in collaboration between the University of Southern Denmark and Aarhus
42 University.
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50 statistical advice and Merete Moll Lund for proofreading the manuscript.
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DATA SHARING STATEMENT

The datasets generated and analysed during the current study are not publicly available due to the data protection regulations of the Danish Data Protection, Statistics Denmark and the Danish Health and Medicines Authority. Access to data is strictly limited to the researchers who have obtained permission for data processing. This permission was granted to the Research Unit of General Practice, Department of Public Health, University of Southern Denmark.

CONTRIBUTORSHIP STATEMENT

SE and DJ participated in the design of the study, development of the questionnaire, the logistics concerning the survey and the drafting of the manuscript. SE moreover did the main work in forming the manuscript and carried out the statistical analyses. RSA and AFP participated in the design of the study, development of the questionnaire and drafting of the manuscript. MMS and RdC participated in the statistical considerations concerning the survey and analyses and MMS carried out the statistical analyses. All authors read and approved the final manuscript.

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Figure 1: Study sample

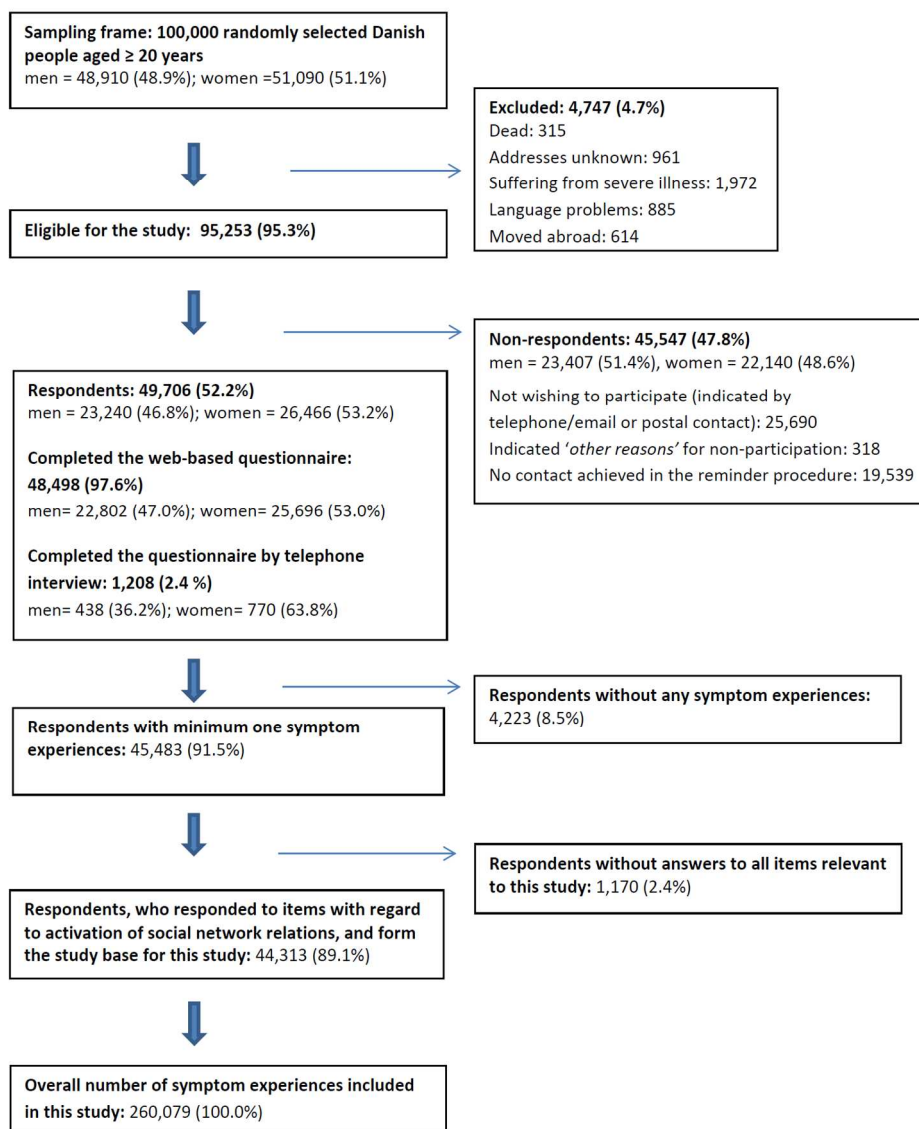


FIGURE 1 - Study sample

135x168mm (300 x 300 DPI)

STROBE 2007 (v4) checklist of items to be included in reports of observational studies in epidemiology*
Checklist for cohort, case-control, and cross-sectional studies (combined)

Section/Topic	Item #	Recommendation	Reported on page #
Title and abstract	1	(a) Indicate the study's design with a commonly used term in the title or the abstract	1-2
		(b) Provide in the abstract an informative and balanced summary of what was done and what was found	2
Introduction			
Background/rationale	2	Explain the scientific background and rationale for the investigation being reported	4-5
Objectives	3	State specific objectives, including any pre-specified hypotheses	4-5
Methods			
Study design	4	Present key elements of study design early in the paper	5
Setting	5	Describe the setting, locations, and relevant dates, including periods of recruitment, exposure, follow-up, and data collection	5
Participants	6	(a) <i>Cohort study</i> —Give the eligibility criteria, and the sources and methods of selection of participants. Describe methods of follow-up <i>Case-control study</i> —Give the eligibility criteria, and the sources and methods of case ascertainment and control selection. Give the rationale for the choice of cases and controls <i>Cross-sectional study</i> —Give the eligibility criteria, and the sources and methods of selection of participants	5
		(b) <i>Cohort study</i> —For matched studies, give matching criteria and number of exposed and unexposed <i>Case-control study</i> —For matched studies, give matching criteria and the number of controls per case	-
Variables	7	Clearly define all outcomes, exposures, predictors, potential confounders, and effect modifiers. Give diagnostic criteria, if applicable	6-7
Data sources/ measurement	8*	For each variable of interest, give sources of data and details of methods of assessment (measurement). Describe comparability of assessment methods if there is more than one group	6,7,8
Bias	9	Describe any efforts to address potential sources of bias	16, 17, 18
Study size	10	Explain how the study size was arrived at	8-9
Quantitative variables	11	Explain how quantitative variables were handled in the analyses. If applicable, describe which groupings were chosen and why	6-7
Statistical methods	12	(a) Describe all statistical methods, including those used to control for confounding	7-8
		(b) Describe any methods used to examine subgroups and interactions	7-8
		(c) Explain how missing data were addressed	-
		(d) <i>Cohort study</i> —If applicable, explain how loss to follow-up was addressed <i>Case-control study</i> —If applicable, explain how matching of cases and controls was addressed	-

		<i>Cross-sectional study</i> —If applicable, describe analytical methods taking account of sampling strategy	
		(e) Describe any sensitivity analyses	-
Results			
Participants	13*	(a) Report numbers of individuals at each stage of study—eg numbers potentially eligible, examined for eligibility, confirmed eligible, included in the study, completing follow-up, and analysed	8-9
		(b) Give reasons for non-participation at each stage	8-9
		(c) Consider use of a flow diagram	8-9
Descriptive data	14*	(a) Give characteristics of study participants (eg demographic, clinical, social) and information on exposures and potential confounders	8
		(b) Indicate number of participants with missing data for each variable of interest	8
		(c) <i>Cohort study</i> —Summarise follow-up time (eg, average and total amount)	-
Outcome data	15*	<i>Cohort study</i> —Report numbers of outcome events or summary measures over time	-
		<i>Case-control study</i> —Report numbers in each exposure category, or summary measures of exposure	-
		<i>Cross-sectional study</i> —Report numbers of outcome events or summary measures	Table 1
Main results	16	(a) Give unadjusted estimates and, if applicable, confounder-adjusted estimates and their precision (eg, 95% confidence interval). Make clear which confounders were adjusted for and why they were included	-
		(b) Report category boundaries when continuous variables were categorized	-
		(c) If relevant, consider translating estimates of relative risk into absolute risk for a meaningful time period	-
Other analyses	17	Report other analyses done—eg analyses of subgroups and interactions, and sensitivity analyses	-
Discussion			
Key results	18	Summarise key results with reference to study objectives	17
Limitations	19	Discuss limitations of the study, taking into account sources of potential bias or imprecision. Discuss both direction and magnitude of any potential bias	17, 18, 19
Interpretation	20	Give a cautious overall interpretation of results considering objectives, limitations, multiplicity of analyses, results from similar studies, and other relevant evidence	19, 20, 21
Generalisability	21	Discuss the generalisability (external validity) of the study results	21
Other information			
Funding	22	Give the source of funding and the role of the funders for the present study and, if applicable, for the original study on which the present article is based	21

*Give information separately for cases and controls in case-control studies and, if applicable, for exposed and unexposed groups in cohort and cross-sectional studies.

Note: An Explanation and Elaboration article discusses each checklist item and gives methodological background and published examples of transparent reporting. The STROBE checklist is best used in conjunction with this article (freely available on the Web sites of PLoS Medicine at <http://www.plosmedicine.org/>, Annals of Internal Medicine at <http://www.annals.org/>, and Epidemiology at <http://www.epidem.com/>). Information on the STROBE Initiative is available at www.strobe-statement.org.