Research article

Revisiting the symptom iceberg based on the Danish symptom cohort – Symptom experiences and healthcare-seeking behaviour in the general Danish population in 2022

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ABSTRACT

Introduction: Healthcare-seeking behaviour may change over time, and some groups are more likely to avoid relevant help seeking, which possibly contributes to social inequity in health. Thus, we developed an expansion of and follow-up to the Danish Symptom Cohort (DaSC) from 2012 and formed the DaSC II, which encompassed a population-based questionnaire study investigating symptoms and healthcare-seeking behaviour. In this paper, we describe the conceptual framework, development and content validity of the questionnaire and a responder analysis of the participants in the DaSC II. We present the symptom iceberg in the Danish general population by estimating the prevalence of symptoms and proportion of contacts to general practitioners (GPs) in 2022. Moreover, we discuss differences in healthcare-seeking behaviour with reference to the 2012 DaSC.

Methods: 100,000 randomly selected Danish citizens aged ≥20 years, along with the 44,713 respondents from the 2012 cohort, were invited to participate in a survey. The questionnaire was pilot and field tested prior to distribution. Descriptive statistics were used to estimate symptom prevalence and proportion of GP contacts, and to execute the respondent analysis.

Results: Nine out of ten respondents reported at least one symptom within the preceding four weeks and reported an average of 4.6 symptoms. One in four symptoms were presented to a GP. The highest proportion of GP contacts was found for haematuria (63.3 %) and shortness of breath (51.8 %). For several symptoms, differences between the sexes were found in relation to both prevalence and GP contacts. The proportion of GP contacts was higher in 2022 than in 2012 and was most pronounced for general, frequently experienced symptoms and to a lesser extent for cancer alarm symptoms.

Conclusion: Many symptoms go unreported, which may delay relevant diagnosis; more research on certain symptom categories and population subgroups is needed. Future studies based on the

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DaSC II form a basis for interventions targeting symptom awareness, healthcare-seeking behaviour and social equity in society and health.

1. Introduction

The experience of bodily sensations is an embodied and everyday phenomenon. As a result of cultural, social, and cognitive influences, bodily sensations are sometimes interpreted as symptoms [1–3]. Anthropological theories suggest that trends of time influence the perception of bodily sensations and semiotics, resulting in increased attention to the timely diagnosis of severe diseases and an increasing need to explain the cause of symptoms [1,4]. The perception of more bodily changes as symptoms of disease may increase the total number of symptoms experienced in the general population [5] and in turn lead to increased healthcare seeking [1,2,6].

The decision to seek healthcare is a complex process [7,8] and only a fraction of all symptoms are presented to a healthcare professional, often referred to as the symptom iceberg [9–11]. Studies have identified several factors influencing healthcare-seeking behaviour, e.g. fear of serious illness, embarrassment and certain lifestyle factors [8,12,13], while a high symptom burden, concern and influence on daily activities facilitate help-seeking behaviour [14,15].

The use of technology, coping strategies and self-care are key elements in symptom management. In recent decades, social inequity in health [16], digital healthcare [17] and the organisation and accessibility of the healthcare system [18] have attracted increasing attention. Being a patient is demanding and requires personal competencies and situational resources, which are needed to access, understand, appraise and use health information and services: also known as health literacy [19].

Current evidence on healthcare-seeking behaviour is mainly based on data from patients recalling their diagnostic pathway after being diagnosed with a specific illness such as e.g., cancer [20], information from GP records [21,22], focus on specific diagnoses [23] or only on symptoms [24,25], anticipated or obsolete data [8,11,26–28]. To our knowledge, no novel studies focusing on a wide spectrum of symptoms and subsequent healthcare-seeking behaviour in the general population exist.

Future initiatives targeting social inequity in health could aim to improve healthcare systems and make them more accommodating and coherent, with a focus on individualised care. To accomplish such aims, updated and exhaustive knowledge is needed about symptoms, healthcare seeking, and challenges encountered in the contact between patients and the healthcare system. We designed and conducted a study called the Danish Symptom Cohort II (DaSC II) in 2022 as a follow-up and expansion of the original Danish Symptom Cohort (DaSC) from 2012 [29]. The overall objective of the DaSC II study was to investigate symptom experiences and healthcare-seeking behaviour in the Danish general population; the possibility of follow-up was facilitated linkage of survey data to data from the Danish national registers. In this paper, we describe the conceptual framework, development and content validity of the questionnaire and a responder analysis of the participants in the DaSC II. We present the symptom iceberg in the Danish general population by estimating the prevalence of symptoms and proportion of contacts to general practitioners (GPs) in 2022. Moreover, we discuss differences in healthcare-seeking behaviour with reference to the 2012 DaSC.

The paper is organised as follows: Section 2 describes the study populations and logistics, the questionnaire development, the pilot and field tests, and applied statistics. Section 3 presents the results, which are then discussed in Sections 4 and 5, followed by the implications and conclusion in Sections 6 and 7, respectively.

2. Materials and methods

2.1. Study population and logistics

We invited two different samples from the Danish population to participate in the study in 2022: 1) A random sample of 100,000 Danish citizens aged 20 years or older, selected from the Danish Civil Registration System using the unique Civil Registration System (CRS) number assigned to each Danish citizen [30]. The random sampling was stratified by sex and age intervals to reflect the general population. 2) A longitudinal sample comprising respondents from 2012. Individuals in the longitudinal sample were excluded from the random sample prior to sampling. This paper will primarily describe the random sample, with selected results from the longitudinal sample shown in supplementary materials.

Both sample groups were invited to participate in an online survey about symptoms and healthcare seeking. The invitation was sent to a personal digital mailbox for public communication, which is linked to the CRS number [30]. About 7 % of the Danish population is exempted from receiving digital mail because of illness, cognitive issues, language barriers, migration, no access to a computer or insufficient internet at home [31,32]. Data were collected between May and July 2022. The study followed STROBE guidelines for reporting of observational studies.

2.2. Questionnaire development

Development of the DaSC II questionnaire followed the COnsensus-based Standards for the selection of health Measurement INstruments (COSMIN) guideline [33,34] and was based on the 2012 questionnaire [29]. Using an online survey made it possible to construct an adaptive structure so that respondents were not presented with irrelevant questions. Validation on each questionnaire page required the completion of all questions before moving on to reduce missing answers.

2.2.1. Conceptual framework

Initially, we scrutinised the conceptual framework and constructs of the questionnaire from 2012. Additionally, we reviewed and thematised 9130 free text comments from the 2012 questionnaire and included them in the conceptual framework to improve comprehensibility and exhaustiveness. In accordance with medical, anthropological and sociological literature, symptom experiences were defined as multidimensional construct embedded in an interplay of biological, psychological and cultural factors [1,35–37]. Healthcare-seeking behaviour was approached in a multifactorial context, e.g. contact to GPs, nurses and physiotherapists, and not defined solely by whether or not an individual sought professional help [1,37]. New constructs were defined based on academic discussions and literature and hypothesized to impact symptom experiences and healthcare seeking.

A user panel was established, consisting of twelve individuals representing the general population, to ensure the relevance to and understanding of the project among the general population. The panel comprised five males and seven females aged 20–87 years who lived in different parts of the country and had diverse educational backgrounds. Early in the development process, the user panel was invited to a meeting to discuss the conceptual framework, the relevance of the constructs and the logistical procedures. Later, they were involved individually in a qualitative pilot test.

2.2.2. Questionnaire domains

The conceptual framework for the 2022 questionnaire resulted in the selection of six domains comprising both formative and reflective models. The six domains are described below and listed in Table 1.

I. **Symptom experiences:** This domain addressed symptom experiences within the four weeks preceding participation in the survey. As in the 2012 questionnaire, we included symptoms of both serious diseases and benign causes. The following three subgroups of symptom categories were identified: 1) lung, gastrointestinal, urogenital and gynaecological symptoms, e.g. of cancers and chronic diseases [38]; 2) frequently experienced symptoms such as headache and tiredness [39]; and 3) symptoms encompassed by Bodily Distress Syndrome (BDS) [40]. Subgroups 1 and 2 included 44 symptoms (32 sex-neutral, 10 female-specific and 2 male-specific); see Table 2.

II. **Symptom characteristics:** The second domain explored the characteristics of each symptom reported, including first occurrence of the symptom, degree of concern about the symptom and the symptom's influence on daily activities.

III. **Actions taken in relation to the symptom:** The third domain consisted of possible actions taken in relation to each reported symptom. Actions included healthcare-seeking behaviour (contacting the GP or other healthcare provider), discussion with friends or relatives and barriers to GP contact. Four of the included barriers were from the Awareness and Beliefs about Cancer Measures (ABC) questionnaire, which has been translated, adapted and validated in Danish [41,42]. The remaining barriers included in the current study were inspired by the Cancer Awareness Measures (CAM) questionnaire [43] and the reflections of the user panel.

IV. **Health behaviour and experiences with the healthcare system:** This domain comprised three new constructs: health literacy, health information-seeking behaviour (HISB) and organisational barriers to healthcare seeking.

Table 1
Questionnaire domains.

1. Symptom experiences
Specific cancer symptoms
Non-specific cancer symptoms
General and frequent symptoms
Symptoms of Bodily Distress Syndrome
2. Symptom characteristics
Onset of symptoms
Symptom concern
Symptom influence on daily activity
3. Actions taken in relation to symptoms
Contact to the general practitioner
Contact to other health professionals
Discussion with social relations
Barriers to healthcare-seeking
4. Knowledge and experience with symptoms, health behaviour, and contacts to the healthcare system
Health literacy
Health information seeking behaviour
Organisational barriers to healthcare-seeking
5. Personal characteristics
Lifestyle factors
Coping
Self-rated health
Chronic disease
6. Healthcare-seeking during and after the first COVID-19 pandemic lockdown
Needing to contact the general practitioner
Experiences and considerations about healthcare-seeking
Healthcare-seeking behaviour post COVID-19

*The questionnaire is available at https://portal.findresearcher.sdu.dk/en/projects/den-danske-symptomkohorte-dask.

Health literacy: Health literacy can be defined as the combination of personal competencies and situational resources needed for people to access, understand, appraise and use information and services to make decisions about health [19]. Several questionnaires and scales measuring health literacy were reviewed [44–47], and two scales were tested in the pilot tests; four domains from the Health Literacy Questionnaire (HLQ) were selected [48]. The HLQ has previously been translated, adapted and validated in Danish [49].

Health Information-Seeking Behaviour: HISB is defined as an active effort to obtain specific information outside the normal patterns of exposure to mediated and interpersonal sources [50]. Literature on and existing scales measuring HISB were explored [17, 50,51], but none were found to be suitable for the DaSC II survey. Thus, an item bank was developed based on the literature [17,50, 52], clinical experience and reflections by the user panel. To keep the construct brief, one question asking about use of specific media (analogue, internet, social media, etc.) to search for information was included, followed by questions eliciting elaboration on the use of digital media.

Organisational barriers to healthcare seeking: Organisational barriers were defined as considerations about contact with the GP relating to any aspect of the communication with general practice and the impact of previous experiences or expectations concerning GP contacts. The questions were developed based on the existing literature [12,53,54] and inspired by the CAM questionnaire [43].

V. **Personal characteristics:** This construct included questions regarding lifestyle factors (smoking status, alcohol consumption, height and weight), self-rated health and chronic disease. Additionally, coping was measured using the Brief Approach/ Avoidance Coping Questionnaire (BACQ) [55], which was translated, adapted and validated in Danish by the project group [56].

VI. **Healthcare seeking during and after the first COVID-19 pandemic lockdown:** An item bank was generated comprising questions about healthcare seeking during the first COVID-19 lockdown in March 2020 and its subsequent consequences. The questions in the item bank were inspired by questions from the CAM questionnaire [57] and by experiences from daily clinical practice and of the user panel.

2.3. Pilot tests

The questionnaire was qualitatively pilot tested twice. In the first pilot, the survey was sent to 26 individuals from academic environments, comprising GPs, younger medical doctors, statisticians, secretaries, anthropologists, psychologists, physiotherapists and occupational therapists. They were asked to complete the questionnaire while taking notes and while taking notes and giving feedback on content, comprehensibility and feasibility. The first pilot test resulted in adjustments to both wording and response categories for the questions about HISB and COVID-19, and minor rephrasing throughout the questionnaire. Four participants were asked to register completion time, which resulted in estimates of between 15 and 26 min.

The second pilot test was carried out among the user panel as individual interviews conducted by a trained interviewer and medical anthropologist. Three of the interviews were in person, whereas the others were conducted virtually. In the interviews, each member was asked to was asked to think aloud as they were completing the questionnaire while the interviewer observed and noted all re-actions and utterances. The interviewer was seated next to the participant in the in-person interviews, and the participants shared their screen with the interviewer in the virtual interviews. The interviewer anecdotally noted that sharing screens resulted in more im-mediate reactions and comments from the participants than the in-person interviews. After the participant had completed the ques-tionnaire, a semi-structured interview was conducted to conducted in which participants were encouraged to elaborate on their thoughts and reactions during the process of completing the questionnaire. The semi-structured interview was supplemented by questions from a pre-prepared interview guide, focusing on the participants' previous experiences with GP contact and their under-standing of certain concepts and wording throughout the questionnaire, including: 'symptoms', 'being worried', 'health professionals', 'seeking information', 'stressful situations' and 'comprehensiveness of the COVID-19 questions'. Following the second pilot, minor changes were made to the wording of the questions about HISB and the COVID-19 lockdown, and the HLQ was included instead of a different scale measuring health literacy [47].

2.4. Field test

Prior to the final distribution of the questionnaire, we conducted a field test among 499 randomly selected Danish citizens aged 20 years or older. The aim of the field test was to test the feasibility, logistics and performance of each domain. In addition, all questions with free text answer boxes throughout the questionnaire were scrutinised to identify any lack of clarity. An invitation describing the overall purpose and legal principles of the study was sent to the digital mailboxes of the invited participants and contained a link to the questionnaire. Invitees exempted from digital mail received the invitation by post. The letter sent by post contained a personal code and the web address of a secure questionnaire web page. After seven days, a reminder was sent to encourage participation among non-respondents. The reminder procedure was repeated three times. The second reminder was followed by a text message encouraging recipients to read the invitation. During the field test, the project group was contactable by phone or email during working hours on weekdays. The field test was conducted in April 2022. Of the 499 invitees, 33 individuals (6.6 %) were invited by post, and 466 in-dividuals (93.4 %) were invited by digital mail. Few of the postal invitees completed the questionnaire. Nine postal invitees or their relatives contacted the project group by phone, eight of whom were excluded from the study due to severe somatic or mental illness, or lack of a computer in their home, Fig. 1. None of the digital invitees contacted the project group. In total, 34 % participated in the field test. Analyses of the results from the field test showed some floor and ceiling effect in the questions concerning HISB and COVID-19. These were reworded and the number of questions reduced. The field test resulted in omitting the postal invitation, the third reminder
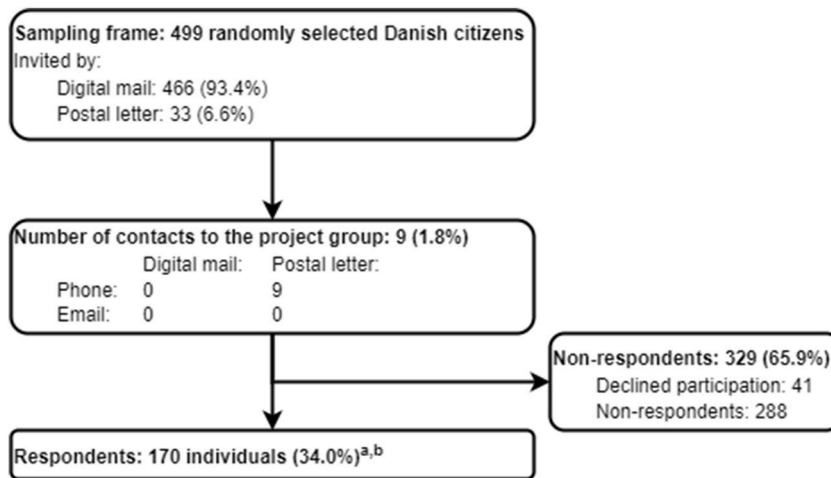
Fig. 1. Flowchart for the field test.

and the reminders by text messages in the final study. Moreover, additional minor changes to wording and the number of questions were made.

2.5. Statistical analyses

The study population characteristics were described using descriptive statistics, including an χ^2 comparison between the study samples and the respondents. Covariates included sex, age, socio-economic factors (marital status, educational level, labour market affiliation and ethnicity) and average number of GP contacts in 2021. Sex and age data were gathered using individual CRS numbers. Socioeconomic data were obtained from Statistics Denmark. For details on registers, coding and categories, see Supplementary Materials, Table S1.

Using descriptive statistics we calculated the mean number of reported symptoms and GP contacts and estimated the prevalence of symptoms and proportion of GP contacts for each of the 44 symptoms in total and by sex. Reporting data for fewer than four individuals is not permitted due to Danish data legislation, and thus some symptoms stratified by sex are not reported. The symptoms were ranked according to symptom frequency, and differences between the sexes were examined using χ^2 tests.

Data analyses were conducted using STATA version 17 (StataCorp, College Station, TX, USA). All tests used a significance level of p < 0.05.

3. Results

Of the 100,000 randomly selected individuals, 7254 (7.3 %) were ineligible due to death or exemption from digital mail, as presented in Fig. 2. Among the eligible invitees, 31,415 individuals completed the questionnaire, yielding a response rate of 33.9 %. More respondents were female, aged 40–69 years, working and had higher educational levels among the respondents than in the
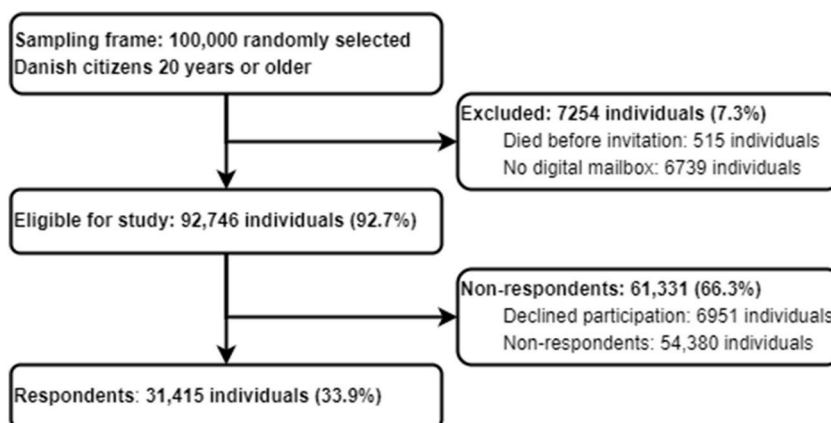

Fig. 2. Flowchart for the random sample.

Table 2
List of symptoms in the 2022 questionnaire.

Respiratory symptoms
Coughing
Shortness of breath
Haemoptysis/Coughing up blood
Hoarseness
Changes to a familiar cough (i.e., changes in strength, frequency, or sputum in a cough you normally have)
Abdominal symptoms
Abdominal pain
Nausea
Vomiting
Blood in vomit
Difficulty swallowing
Changes in stool texture (i.e., harder or lumpier stools than usual, or the opposite, looser and waterier stools than usual)
Changes in bowel movement frequency (i.e., passing stools more often, or less often than usual)
Blood in stool
Black stool
Diarrhoea
Constipation
Abdominal bloating[a]
Increased waist circumference (e.g., your pants feel tighter than usual)[a]
Gynaecological symptoms
Pelvic pain[a]
Postmenopausal bleeding[c]
Vaginal bleeding after intercourse[a]
Pain during intercourse[a]
Pelvic pressure[a]
Heavy and/or prolonged menstrual bleeding[d]
Heavy menstrual cramps[d]
Irregular menstrual bleeding[d]
Urological symptoms
Blood in semen[b]
Erectile dysfunction[b]
Haematuria/blood in urine
Frequent urination
Night-time urination
Difficulty emptying the bladder
Urge incontinence
Stress incontinence
Urinary leakage
General and frequent symptoms
Tiredness
Exhausted
Feeling unwell
Fever
Weight loss of more than 2 kg without making an effort
Loss of appetite
Dizziness
Headache
Back pain

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[a] Only females.
[b] Only males.
[c] Only postmenopausal females.
[d] Only pre-menopausal females.

Table 3

Descriptive characteristics of the total sample, respondents, and non-respondents in the random sample (N: 100,000).

	Total sample		Respondents		Non-respondents		
	N	%	n	%	n	%	*P*-value[a]
Total	100,000	100.0	31,415	100.0	68,585	100.0	
Sex							<0.01
Female	50,686	50.7	17,936	57.1	32,750	47.8	
Male	49,314	49.3	13,479	42.9	35,835	52.3	
Age groups, years							<0.01
20-39	32,720	32.7	6915	22.0	25,805	37.6	
40-59	33,474	33.5	11,407	36.3	22,067	32.2	
60-79	27,383	27.4	11,715	37.3	15,668	22.8	
80+	6423	6.4	1378	4.4	5045	7.4	
Marital status							<0.01
Single	37,088	37.0	9448	30.1	27,640	40.3	
Married/living together	62,359	62.4	21,927	69.8	40,432	59.0	
Missing	553	0.6	40	0.1	513	0.8	
Educational level							<0.01
Low (<10 years)	12,032	12.0	2418	7.7	9614	14.0	
Medium (10–15 years)	51,149	51.2	15,522	49.4	35,627	52.0	
High (>15 years)	35,950	36.0	13,389	42.6	22,561	32.9	
Missing	869	0.9	86	0.3	783	1.1	
Labor market affiliation							<0.01
Working	62,749	62.8	19,873	63.3	42,876	62.5	
Pensioners	22,355	22.4	8063	25.7	14,292	20.8	
Out of workforce	9404	9.4	2215	7.1	7189	10.5	
Disability pension	5039	5.0	1239	3.9	3800	5.5	
Missing	453	0.5	25	0.1	428	0.6	
Ethnicity							<0.01
Danish	84,776	84.8	28,791	91.6	55,985	81.6	
Immigrants or descendants of immigrants	14,671	14.7	2584	8.2	12,087	17.6	
Missing	553	0.6	40	0.1	513	0.8	

[a] Test for difference between respondents and non-respondents by X2 test, statistically significant p-value <0.05.

random study sample. Furthermore, more were married or living with a partner and were of Danish ethnicity, as shown in Table 3. From the longitudinal sample, 22,388 (52.4 %) individuals answered the questionnaire. Further results for the longitudinal sample are reported in Supplementary Materials, Table S2 and Fig. S2.

3.1. The symptom iceberg

Of the 31,415 respondents, almost nine in ten (86.5 %) reported at least one symptom (males 83.4 %; females 88.8 %). The average number of reported symptoms was 4.6 (males 3.6; females 5.6), and 27.7 % of the symptoms had led to GP contact. This percentage was slightly higher for males (28.3 %) than females (27.4 %); 41.5 % of all the respondents reported GP contact regarding at least one symptom. The number of reported symptoms ranged from 0 to 34 for females (of 42 possible symptoms) and 0 to 32 (of 34 possible symptoms) for males.

The symptom iceberg, in terms of the prevalence of each symptom reported and proportion of GP contacts, is shown in Table 4 and illustrated in Fig. 3. The most frequently reported symptoms were tiredness (50.7 %), back pain (34.9 %) and headache (35 %). Haemoptysis (0.3 %), vomiting blood (0.1 %) and blood in semen (0.5 %) were rare. For two in three sex-neutral symptoms (65.6 %), the prevalence of symptoms reported was higher for females (p < 0.01), yet males reported a higher prevalence of coughing up blood, black stool and some urinary tract symptoms (difficulties emptying the bladder and night-time urination), Table 4.

The proportion of GP contacts ranged from 16 % (increased waist circumference) to 63.3 % (haematuria). For the five symptoms including signs of blood, which are often referred to as cancer symptoms (haemoptysis, blood in vomiting, post-menopausal bleeding, rectal bleeding and blood in semen), the average proportion of GP contacts was 40.2 % (ranging from 28.4 % for haemoptysis to 63.3 % for haematuria), while the average proportion of GP contacts was 28.8 % for the three most general and frequently experienced symptoms (tiredness, headache and back pain), Table 4.

For more than two in three sex-neutral symptoms, we found differences in the proportion of GP contacts between the sexes. For most symptoms, females had a higher proportion of GP contact, but for abdominal pain, back pain and four urological symptoms, males had a higher proportion of GP contact, Table 4.

The corresponding table and figure for the longitudinal sample are shown in Supplementary Materials, Table S3 and Fig. S3.

Table 4

Symptom prevalence and proportions of contact to general practice in total and by sex in the random sample (N = 31,415).

	Symptom prevalence				Proportion of contacts to general practice			
	Total n (%)	**Female** n (%)	**Male** n (%)	*p-value*[e]	**Total** n (%)	**Female** n (%)	**Male** n (%)	*p-value*[e]
Tiredness	15,920 (50.7)	9778(61.4)	6142(38.6)	<0.01	4165(26.2)	2719(27.8)	1446 (23.5)	<0.01
Headache	10,996 (35.0)	7641(69.5)	3355(30.5)	<0.01	2612(23.8)	1918(25.1)	694(20.7)	<0.01
Back pain	10,977 (34.9)	6550(59.7)	4427(40.3)	<0.01	4136(37.7)	2447(37.4)	1689 (38.2)	<0.01
Abdominal bloating[a]	6112(34.1)	6112(100.0)	–	–	987(16.1)	987(16.1)	–	–
Exhausted	10694(34.0)	6838(63.9)	3856(36.1)	<0.01	3060(28.6)	2097(30.7)	963(25.0)	<0.01
Coughing	8366(26.6)	4799(57.4)	3567(42.6)	0.56	1992(23.8)	1190(24.8)	802(22.5)	0.01
Erectile dysfunction[b]	2896(21.5)	–	2896 (100.0)	<0.01	1113(38.4)	–	1113 (38.4)	–
Changes in stool texture	6330(20.1)	3738(59.1)	2592(40.9)	<0.01	1127(17.8)	696(18.6)	431(16.6)	<0.01
Dizziness	5905(18.8)	3917(66.3)	1988(33.7)	<0.01	2087(35.3)	1386(35.4)	701(35.3)	<0.01
Abdominal pain	5842(18.6)	4112(70.4)	1730(29.6)	<0.01	1884(32.2)	1297(31.5)	587(33.9)	<0.01
Feeling unwell	4916(15.6)	3222(65.5)	1694(34.5)	<0.01	1384(28.2)	934(29.0)	450(26.6)	<0.01
Irregular menstrual bleeding[d]	2766(15.4)	2766(100.0)	–	–	758(27.4)	758(27.4)	–	–
Constipation	4336(13.8)	3033(69.9)	1303(30.1)	<0.01	840(19.4)	590(19.5)	250(19.2)	<0.01
Nausea	4280(13.6)	3170(74.1)	1110(25.9)	<0.01	1055(24.6)	796(25.1)	259(23.3)	<0.01
Heavy menstrual cramps[d]	2343(13.1)	2343(100.0)	–	–	550(23.5)	550(23.5)	–	–
Changes in stool frequency	3437(10.9)	2176(63.3)	1261(36.7)	<0.01	664(19.3)	425(19.5)	239(19.0)	<0.01
Stress incontinence	3381(10.8)	3154(93.3)	227(6.7)	<0.01	752(22.2)	666(21.1)	86(37.9)	<0.01
Shortness of breath	3379(10.8)	1926(57.0)	1453(43.0)	0.91	1750(51.8)	1024(53.2)	726(50.0)	0.22
Heavy/prolonged menstrual bleeding[d]	1912(10.7)	1912(100.0)	–	–	541(28.3)	541(28.3)	–	–
Night-time urination >3 times	3190(10.2)	1546(48.5)	1644(51.5)	<0.01	1077(33.8)	438(28.3)	639(38.9)	<0.01
Pelvic pain	3180(17.7)	3180(100.0)	–	–	935(29.4)	935(29.4)	–	–
Frequent urination	3095(9.9)	1630(52.7)	1465(47.3)	<0.01	902(29.1)	429(26.3)	473(32.3)	<0.01
Diarrhoea	3066(9.8)	1805(58.9)	1261(41.1)	0.04	728(23.7)	460(25.5)	268(21.3)	<0.01
Pelvic pressure	1753(9.8)	1753(100.0)	–	–	460(26.2)	460(26.2)	–	–
Difficult emptying the bladder	2645(8.4)	1078(40.8)	1567(59.2)	<0.01	938(35.5)	325(30.1)	613(39.1)	<0.01
Hoarseness	2580(8.2)	1628(63.1)	952(36.9)	<0.01	466(18.1)	299(18.4)	167(17.5)	<0.01
Loss of appetite	2506(8.0)	1585(63.2)	921(36.8)	<0.01	592(23.6)	406(25.6)	186(20.2)	<0.01
Pain during intercourse[a]	1383(7.7)	1383(100.0)	–	–	460(33.3)	460(33.3)	–	–
Urge incontinence	1851(5.9)	1203(65.0)	648(35.0)	<0.01	571(30.8)	358(29.8)	213(32.9)	0.01
Increased waist circumference[a]	1835(5.8)	1835(100.0)	–	–	293(16.0)	293(16.0)	–	–
Difficulties swallowing	1385(4.4)	776(56.0)	609(44.0)	0.41	473(34.2)	280(36.1)	193(31.7)	0.35
Fever	1349(4.3)	898(66.6)	451(33.4)	<0.01	309(22.9)	217(24.2)	92(20.4)	<0.01
Blood in stool	1301(4.1)	771(59.3)	530(40.7)	0.11	499(38.4)	300(38.9)	199(37.5)	0.17
Urinary leakage	1093(3.5)	761(69.6)	332(30.4)	<0.01	427(39.1)	312(41.0)	115(34.6)	<0.01
Bleeding during intercourse[a]	541(3.0)	541(100.0)	–	–	176(32.5)	176(32.5)	–	–
Weight loss	788(2.5)	433(54.9)	355(45.1)	0.22	252(32.0)	146(33.7)	106(29.9)	0.79
Changes to a familiar cough	447(1.4)	240(53.7)	207(46.3)	0.14	129(28.9)	81(33.8)	48(23.2)	0.19
Black stool	304(1.0)	144(47.4)	160(52.6)	<0.01	61(20.1)	33(22.9)	28(17.5)	0.64
Vomiting	289(0.9)	185(64.0)	104(36.0)	0.02	92(31.8)	61(33.0)	31(29.8)	0.07
Haematuria	169(0.5)	91(53.8)	78(46.2)	0.39	107(63.3)	61(67.0)	46(59.0)	0.99
Postmenopausal bleeding[c]	88(0.5)	88(100.0)	–	–	30(34.1)	30(34.1)	–	–
Blood in semen[b]	67(0.5)	–	67(100.0)	–	30(44.8)	–	30(44.8)	–
Haemoptysis	102(0.3)	43(42.2)	59(57.8)	<0.01	29(28.4)	16(37.2)	13(22.0)	0.83
Blood in vomit	36(0.1)	18(50.0)	18(50.0)	0.39	12(33.3)	8(44.4)	4(22.2)	0.50

[a] Only females.

[b] Only males.

[c] Only postmenopausal females.

[d] Only pre-menopausal females.

[e] Test for difference between sexes by X^2 test, statistically significant p-value <0.05.
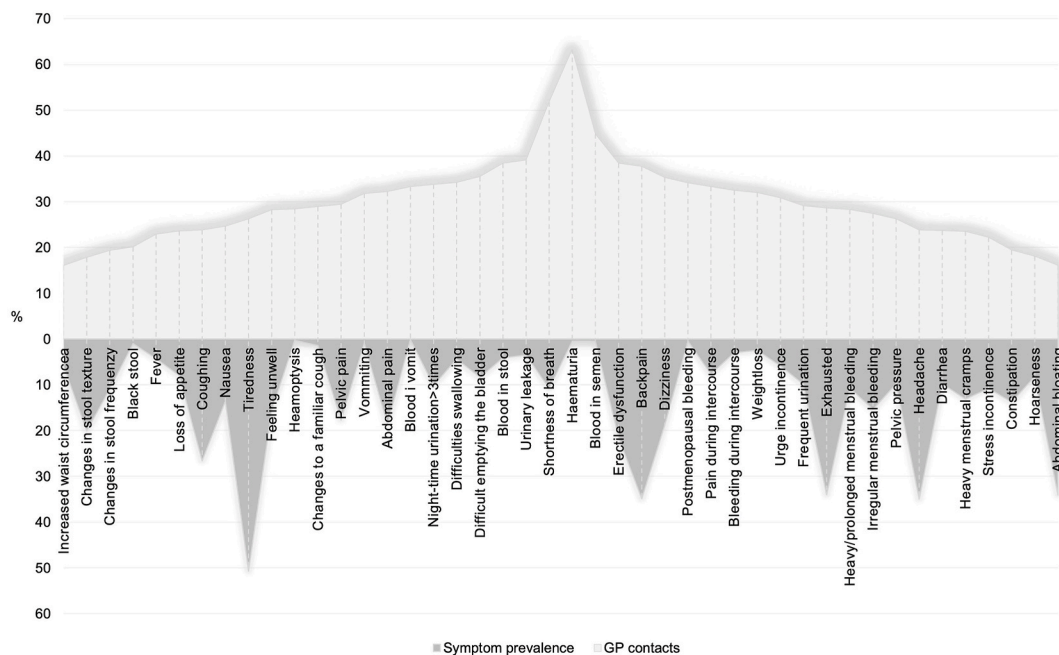
Fig. 3. The symptom iceberg for the random sample: Prevalence of symptom experiences and proportions of contacts to the general practitioner (GP) (N = 31,415).

4. Discussion

4.1. Summary of main findings

The development of the DaSC II questionnaire followed international standards. The pilot- and field tests showed good content validity, including comprehensibility, face validity and feasibility. The DaSC II comprises two study populations, including 31,415 individuals in the random sample and 22,388 individuals in the longitudinal sample, yielding response rates of 33.9 % and 52.4 %, respectively. A higher proportion of the respondents were females, middle aged and working, yet the study populations comprised representatives of all socio-economic groups.

The only symptoms with a proportion of GP contact over 40 % were haematuria (63.3 %), shortness of breath (51.8 %) and blood in semen (44.8 %). Approximately one in four respondents had contacted their GP about general symptoms such as tiredness, headache and back pain, while two in five had contacted their GP about alarm symptoms including signs of blood, yet with considerable variety between symptoms.

4.2. Strengths and limitations

The 2022 questionnaire was developed following the COSMIN guideline [33,34], which enhances the transparency of the process. The questionnaire was pilot tested twice and showed good face validity, comprehensibility and feasibility. Based on the field test showing that individuals without digital mail were unlikely to participate, we omitted postal invitations to participate in the 2022 survey to avoid the unnecessary disturbance of potential participants and their relatives. Although this could induce selection bias, we consider the decision conscientious and ethical. The final study population comprises representatives of the oldest age groups, individuals with low educational levels, individuals of non-Danish ethnicities and individuals outside the labour market, enabling analyses among subgroups.

The DaSC II questionnaire consists of both reflective scales and formative questions. All the reflective scales have been translated and validated in a Danish context, which enhances credibility [41,49,56]. Most of the formative questions were repeated from the 2012 questionnaire or inspired by international questionnaires and existing literature within the field.

The response rate of 33.9 % in the random sample is slightly lower than desired but is comparable to another large-scale Danish population-based study [58]. Both this study and the study by Sørensen et al. are based on randomly selected samples of the general population. The response rate of 52.4 % in the longitudinal sample is satisfactory and comparable to another large-scale study conducted in a selected sample of the general population [59]. Our differing response rates may be related to the fact that the longitudinal sample consists of previous participants, who are probably more likely to participate. Initiatives to enhance the possibility of higher response rates were explored prior to survey distribution. Based on the existing evidence and discussions with the user panel, we chose to include an easily read invitation with an aesthetically pleasing layout [60] and offered a lottery for a gift card of 330 euros as a

potential motivating factor for participation [61].

The DaSC II study enables both the investigation of a new random cohort and a follow-up investigation of participants from 2012 and allows analysis of the development of symptom experiences and healthcare-seeking behaviour during the last decade at both an individual and a population-based level. Furthermore, linking DaSC II data to Danish registers enables follow-up on diagnostic evaluations, diagnoses and use of healthcare services.

Individuals experiencing many symptoms may be more likely to participate in a survey about symptoms, which may induce a risk of overestimating the symptom prevalence. However, individuals with many symptoms may not have the capacity to answer a comprehensive questionnaire, which may risk of underestimation [62]. Selection bias cannot be ruled out, but we sought to minimise bias as described above and by offering participants the opportunity to contact the project group by phone or email in case of technical or comprehension challenges.

Participants were asked to recall symptoms experienced within the four weeks preceding participation in the survey and whether they had been in contact with their GP. This time span was considered reasonable to assume the adequate recall of symptoms and healthcare-seeking behaviour, thus reducing the risk of recall bias [63]. Nevertheless, recall bias must be considered in future studies, since the ability to remember may be affected by several aspects, such as the number of symptoms, GP contacts, concern, and so on.

5. Discussion of the symptom iceberg

The present study is in line with previous studies investigating symptoms in the general population which indicate that only the top of the symptom iceberg is presented to the GP [11,39]. Nevertheless, there are noticeable differences between the present results and results from the first DaSC study [39]. The average number of 4.6 reported symptoms per individual in 2022 is lower than in 2012 (5.8 symptoms), which is primarily attributable to a lower number of symptoms reported by males (3.6, compared to 4.8 in 2012). In contrast, GP contacts were reported for more than one in four symptoms in 2022, whereas only one in five symptoms were presented to a GP in 2012 [15]. In 2012, differences in the proportion of GP contacts between the sexes were found for one in three symptoms [39], while differences were found for more than two in three symptoms in 2022. Reasons for differences between the sexes may be due to changes in perception of bodily sensations, such as a higher threshold for what is perceived as a symptom among males. Ballering et al. have suggested that differences in healthcare-seeking behaviour between males and females are not explained by sex, but rather by gender differences [64]. Investigation of this, however, is beyond the scope of the present study.

The lower symptom prevalence in 2022 than 2012 is incompatible with theories suggesting that changes in symptom perception and semiotics during the last decade have increased the likelihood of bodily sensations being interpreted as symptoms [1,5]. Yet the increase in the proportion of GP contacts accords with theories arguing that a greater need for explanations of symptoms and requests to rule out severe illnesses among the general population, society and physicians may facilitate higher rates of healthcare seeking [2,4]. Simultaneous with the overall increase in healthcare seeking, the number of symptoms with a proportion of GP contacts higher than 40 % has declined over the last decade [39]. This may imply that the increase in healthcare seeking is general, rather than due to higher rates for certain symptoms such as potential alarm symptoms. Future studies should explore such changes within different subgroups of individuals and symptom categories.

From a physician's perspective, alarm symptoms including blood should prompt healthcare seeking. Yet the proportion of GP contacts for alarm symptoms is still rather low and is especially notable for most symptoms including blood. This is surprising given the extensive efforts over the last decade of the Danish Cancer Society, among others, to improve awareness of and encourage healthcare seeking for symptoms of cancer [65].

While healthcare seeking in relation to some alarm symptoms seems lower in 2022, the proportion of GP contacts in relation to frequent general symptoms such as tiredness, headache and back pain are higher in 2022 than in 2012 [39]. Several possible explanations for this may exist, hence the time trends and factors influencing the perception of symptoms and healthcare-seeking behaviour are multiple. For instance, the Corona Virus pandemic may have heightened awareness regarding taking action acting when experiencing symptoms among the general population. Likewise, public awareness campaigns conducted during the last decade could be of importance for the increase in healthcare-seeking from 2012 to 2022 [65]. Anthropological theories point to an increased desire to understand and explain bodily sensations and symptoms in both the general population and among physicians. Such requests are also likely to facilitate healthcare seeking [1,66].

6. Implications

The overall increase in GP contacts over the past decade, along with a rising awareness of the risk and fear of illnesses, may reinforce the need for more contacts to the healthcare system in the future [1]. This will be a challenge for all stakeholders, including healthcare professionals and health organisers. By following subgroups of the longitudinal sample, e.g. individuals with multiple physical symptoms, we can investigate changes in symptom frequency, coping strategies and other factors affecting the interpretation of and actions related to specific symptoms.

Despite the overall increase in GP contacts, this was not uniformly true for all symptoms; it must be kept in mind that healthcare seeking is a demanding task, and some individuals are more likely to avoid or postpone healthcare seeking despite experiencing severe symptoms [8]. These groups may also be at the highest risk of serious illnesses. The DaSC II study will add to the knowledge base concerning factors contributing to social inequity in health and healthcare-seeking behaviour and build a foundation for a more accommodating and versatile healthcare system. Enhanced focus on subgroups, e.g. individuals with health literacy challenges, the high use of avoidant coping strategies and individuals who experience multiple barriers to healthcare seeking, could improve both

communication with and access to the healthcare system, as well as point to structural and educational changes needed to generate a healthcare system that is more accommodating to the needs and resources of individual citizens.

In healthcare systems where qualified personnel, resources and time are increasingly scarce, prioritisation will be necessary to balance supply and demand in the future. An important part of this will be the individual's ability to interpret and act on symptoms, including the ability to make adequate decisions regarding which symptoms to present to the GP. Knowledge about organisational barriers to healthcare-seeking may also point to areas where the availability or organisation of primary care can be improved.

7. Conclusion

The DaSC II study comprises two study populations, including 31,415 individuals in the random sample and 22,388 individuals in the longitudinal sample, yielding response rates of 33.9 % and 52.4 %, respectively. The 2022 symptom iceberg revealed that nine in ten respondents reported at least one symptom within the preceding four weeks and that one in four symptoms were presented to the GP. For most symptoms, differences in healthcare-seeking behaviour were found between the sexes, and females reported a higher proportion of GP contacts for most symptoms than males. The average number of symptoms reported was lower in 2022 than in 2012. However, the proportion of symptoms presented to the GP was higher, a finding which was most pronounced for general and frequent symptoms and to a lesser extent for cancer symptoms.

Future studies based on the DaSC II survey will investigate factors influencing healthcare-seeking behaviour with different categories of symptoms among subgroups of the general population and serve as a basis for future interventions targeting symptom awareness, adequate healthcare-seeking behaviour and social equity in both society and healthcare systems.

Ethics

The respondents were informed that participation in the study was voluntary. The invitation letter provided thorough information about the purpose and content of the questionnaire and explained that by answering the survey participants consented to use of their data for research purposes according to the Danish Data Legislation §10 (https://www.retsinformation.dk/eli/lta/2018/502). Respondents were informed that there would be no clinical follow-up, and they were instructed to contact their doctor in case of concerns about symptoms. The project was conducted and the data are stored in alignment with Danish data protection legislation and the General Data Protection Regulation (GDPR). The project was reviewed and approved by the Research Ethics Committee at the University of Southern Denmark (case no. 21/29156) December 15th, 2021 and has been registered with the Danish Data Protection Agency (j.no. 2011-41-6651) through the Research and Innovation Organisation (RIO), University of Southern Denmark (Project number 10.104).

Data availability

The datasets generated and analysed in the current study are not publicly available and cannot be shared due to the data protection regulations imposed by the Danish Data Protection Agency. Access to the 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. Further enquiries can be made to PI Dorte Ejg Jarbøl, djarbol@health.sdu.dk.

CRediT authorship contribution statement

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Declaration of competing interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

Appendix A. Supplementary data

Supplementary data to this article can be found online at https://doi.org/10.1016/j.heliyon.2024.e31090.

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