BMJ Open What are the prevalence and predictors of psychosocial healthcare among patients with heart disease? A nationwide population-based cohort study

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ABSTRACT

Objectives Psychosocial healthcare is recommended, but little is known about how patients perceive the level of care and whether subgroups of patients experience less psychosocial healthcare than others. We examined the prevalence of patient-reported psychosocial healthcare and factors predicting patient-reported lack of psychosocial healthcare among patients with heart disease.

Design A cohort study.

Setting Denmark, nationwide.

Participants A registry-based random sample of 5000 patients with incident heart disease in 2013.

Measures Patient-reported psychosocial healthcare was obtained from a survey and potential predictors before disease onset from registries. We used multivariable logistic regression analysis to determine predictors of patient-reported lack of care.

Results We received responses from 56%; 40% reported lacking information on psychosocial aspects, 51% lacking psychosocial rehabilitation and support and 32% reported lacking both types of psychosocial healthcare. The type of heart disease was the strongest predictor of patient-reported lack of psychosocial healthcare, especially among patients with atrial fibrillation (OR: 3.11-3.98). Older age (OR: 1.48-2.05), female gender (OR: 1.27-1.53) and no contact with general practitioner (OR: 1.47-1.84) also predicted patientreported lack of psychosocial healthcare. Patients outside the labour force (OR: 1.29) and living in the capital region (OR: 1.50) more frequently reported lacking psychosocial rehabilitation and support, and patients with recent (OR: 1.63) or past (OR: 1.33) anxiety or depression and severe comorbidities (OR: 1.34) more frequently reported lacking both types of psychosocial healthcare.

Conclusions Many patients with heart disease reported lacking psychosocial healthcare. Importantly, patients who most need psychosocial healthcare are not those who report receiving it. Our results call for action to translate guidelines into clinical practice.

INTRODUCTION

It has long been established that psychosocial factors, such as depression and loneliness, increase the risk of incident heart disease.^{1–6} Psychosocial risk factors are also common among patients with established heart disease

Strengths and limitations of this study

- The study is based on a large random populationbased sample of 5000 patients with heart disease selected in a nationwide patient registry minimising selection bias.
- Potential predictors were measured before disease onset in a cohort of incident cases.
- Data sources at the individual level was linked using a unique personal identification number.
- We obtained the outcome of patient-reported psychosocial healthcare from a survey covering all sectors.
- There is no consensus on the definition of psychosocial healthcare.

with, for example, depression, anxiety and loneliness being prevalent in 20%-30% of most diagnostic groups.^{7–9} These conditions increase the risk of poor quality of life and poor prognosis in patients with heart disease,^{1-3 8 10 11} through behavioural mechanisms (eg, smoking, poor dietary habits, physical inactivity, non-adherence to medication and participation in cardiac rehabilitation) and biological mechanisms (eg, autonomic nervous system dysfunction, endothelial dysfunction, low-grade inflammation and increased stress reactivity).^{3 5 8 12} While the absence of psychosocial risk factors is not sufficient to ensure psychosocial health, which includes emotional and social wellbeing, it is an important step.

The European Society of Cardiology (ESC) highlights the role of the healthcare system in preventing and treating psychosocial risk factors.¹ They emphasise that healthcare professionals in clinical practice can directly support patients through assessment of psychosocial risk factors, encouraging patients to express their emotions and recommending interventions targeting psychosocial

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risk factors.¹ In line with this, patients emphasise psychosocial support as an important aspect of high-quality care.^{13–17}

Even though psychosocial healthcare is recommended in guidelines, there is no consensus on what it is or how it is achieved, and definitions are often poorly described, which complicates its assessment.^{13 15 18 19} Patient-centred care, patient-centred communication, screening for psychosocial risk factors, multimodal interventions with psychosocial approaches, psychotherapy and psychotropic drugs are all examples of psychosocial healthcare,^{1 20 21} and even within these concepts there is no agreement on the definition and how to measure it. Nevertheless, there is evidence that some types of psychosocial healthcare are associated with improved outcomes.^{1 18 20–23} For instance, a recent meta-analysis highlights that psychological interventions in patients with ischaemic heart disease (IHD) decreased psychological symptoms and cardiovascular mortality, while evidence is though still lacking on overall mortality and readmissions.¹⁸

Studies suggest that psychosocial healthcare is an area in need of improvement. It is one of the most common problem areas within the healthcare system reported through surveys by other patient groups,^{16 24} but psychosocial healthcare could be assumed to be more widespread among heart patients due to the earlier focus on psychosocial risk factors and guideline recommendations.^{25 26} However, studies among heart patients have identified inadequate screening for anxiety and depression in hospital-based cardiac rehabilitation and low prescription of antidepressants and anxiolytic medication at hospital discharge.⁹²⁷ Still, patients may have received other types of psychosocial healthcare and in other care settings throughout their patient journey. More studies are needed to evaluate if the recommendations on psychosocial healthcare among patients with heart disease are being implemented in clinical practice.⁵¹⁰

Patients can offer unique knowledge of their own disease and treatment journey, and patients' perspectives are emphasised as essential for assessing and improving healthcare services by the WHO and the American Institute of Medicine.²⁸ ²⁹ Accordingly, survey instruments measuring patient experience of healthcare quality have become a widespread and acknowledged tool to identify gaps and drive quality improvement.³⁰ Studies suggest that age,^{7 16 31-34} gender,^{7 16 31-34} ethnic

Studies suggest that age,^{7 16 31–34} gender,^{7 16 31–34} ethnic background,³¹ low socioeconomic status,^{9 31} cohabitation,^{7 31 33} body mass index (BMI),^{9 31 35} poor health status and comorbidity,^{7 16 31 32} mental health,^{31 32 34} geographic region³¹ and contact to general practitioner (GP)³⁶ are associated with patient-reported psychosocial healthcare. However, the results are inconsistent and based on qualitative and cross-sectional studies among other patient groups and within patient experience, satisfaction and communication in general and on patient-reported psychosocial health.

In this study, we examined the prevalence of patientreported psychosocial healthcare and predictors of the reported lack of psychosocial healthcare among patients with heart disease through a survey taking account of the entire patient journey and predictors obtained before disease onset from national registries.

METHODS

Study design

This is a nationwide population-based cohort study with prospectively collected data from registries. Data sources at the individual level were linked using a unique personal identification number which is available in all registries in Denmark.³⁷

Setting

The study was conducted in Denmark (5.7 million inhabitants). Denmark's healthcare system is universal with free and equal access to healthcare for all residents. Hospitals have inpatient and outpatient clinics; and GPs and municipalities are responsible for disease rehabilitation outside hospitals.

Population

The cohort consisted of a stratified random populationbased sample of 5000 patients with incident heart disease diagnosed in 2013 selected from the Danish National Patient Registry (NPR) limiting selection bias. The NPR was established in 1977 and covers all inpatient and outpatient hospital contacts.³⁸ Patients were diagnosed with atrial fibrillation (AF) (International Classification of Diseases (ICD)-10: I48), heart failure (HF) (ICD-10: I11.0, I13.0, I13.2, I42.0, I150), heart valve disease with heart valve surgery (HVS) (the Nordic Medico-Statistical Committee (NOMESCO) Classification of Surgical Procedures: KFG, KFK, KFM, KFJE, KFJF) or IHD (ICD-10: I20-I25), had none of the specified heart diseases in the previous 5 years (2008–2012) and were \geq 35 years of age, residents of Denmark and alive when the sample was established in October 2014. More information on the population is available in a previous publication.¹⁷

Questionnaire-based survey

To examine heart patients' experiences with the Danish healthcare system and their health status, we conducted a survey in October to December 2014 covering a patient journey across sectors. The survey was posted to the sample group including a prepaid envelope. Patients' home addresses were obtained from the Danish Civil Registration System (CRS). This study examines patientreported experiences with psychosocial healthcare based on elements from the survey. The questionnaire was developed based on a literature review, three focus group interviews with 19 patients, one focus group with four relatives and individual interviews with eight health professionals working with heart patients (eg, cardiologist, nurse, psychologist). It was also pilot tested among 15 patients using cognitive interviewing techniques. The focus was to ensure the questionnaire covered aspects important to patients. A psychometric evaluation resulted

Subscale	Question	Reply options, categorisation and values
Patient-reported information on psychosocial aspects	(A1) Do you feel informed about the emotional reactions you may experience as a result of your disease?(A2) Do you feel informed about the emotional reactions your relatives may experience as a result of your disease?(A3) Do you feel informed about how the disease may affect your relationship with family, friends and others?	3: Yes, to a great degree 2: Yes, to some degree 1: To a lesser degree 0: No (no, not at all; do not know)
	(A4) Do you feel informed about what the disease can mean for your sex life and relationships?	
Patient-reported psychosocial rehabilitation and support	(B1) Did healthcare staff at any time ask whether you had experienced emotional problems in connection with your disease?	 Yes (yes, at the hospital; yes, at my general practitioner; yes, in my municipality) No (no, not at any time; do not know)
	(B2) Have you been offered emotional support in connection with your disease?(B3) Have you been offered guidance on sex life and relationships in connection with your disease?	 Yes (yes, and I accepted the offer; yes, but I rejected the offer) No (no; do not know)

A1–A4 and B1–B3 are referring to the variable names in online supplemental figure 1.

in a patient-reported experience measure with nine dimensions of healthcare quality showing high construct validity and internal consistency. Two of these dimensions concerned psychosocial healthcare: information on psychosocial aspects and rehabilitation and support. The development of the questionnaire has been described in detail in the previous study.¹⁷

Outcome measures

We defined patient-reported psychosocial healthcare as patients' experiences of receiving information and being offered support regarding psychosocial aspects of importance according to heart patients. It consisted of four items measuring patient-reported information on psychosocial aspects which concerned whether patients experienced being offered information on emotional reactions (own and relatives) and on how the disease could influence social life and sex life, and three items measuring patientreported psychosocial rehabilitation and support which concerned patients experiences of being offered support and guidance on these matters, and if healthcare professional had asked about emotional problems (table 1). All questions covered the patient journey from first contact with the healthcare system to the inpatient and outpatient treatment and rehabilitation at the hospital, the GP and the municipality. The responses for the two subscales were added and then dichotomised into nothing (score=0) versus something (score≥1). We chose this conservative categorisation because, although guidelines recommend that patients receive psychosocial healthcare, no guidelines indicate the level of this care. We also combined the two outcomes to assess the proportion of patients reporting lack of both types of psychosocial healthcare. Psychometric evaluation assessed the two-factor model

for patient-reported psychosocial healthcare and overall indicated a good model (online supplemental figure 1).

Potential predictor variables

Potential predictors of lack of patient-reported psychosocial healthcare were obtained before disease onset from national registries. Selection of the potential predictors: age, gender, ethnic background, educational level, income, employment status, cohabitation, BMI and left ventricular ejection fraction (LVEF), comorbidity, anxiety or depression, region and contact to GP were based on literature,^{7 16 31-36} and confirmed in consultation with two cardiologists, a GP, a nurse and a psychologist. From these consultations three additional possible predictors (smoking status, type of heart disease and acute vs planned hospitalisation) were chosen. For instance, type of heart disease was proposed as a predictor because the Danish national clinical guidelines on CR only covered IHD, HF and HVS and not AF. Also, the guidelines provided a strong recommendation for psychosocial healthcare to patients with IHD, but due to lack of evidence it was only stated to be good practice to patients with HF and HVS.³⁹ The availability of a wide range of information in high-quality national registries enabled us to choose the most appropriate indicators. For an overview of the possible predictors and their data sources see online supplemental figure 2.

Demographic and socioeconomic factors

We obtained information on age (at diagnosis), gender, ethnic background (Danish origin vs immigrants or descendants) and cohabitation (married or cohabiting vs single) from CRS on 31 December 2012. We obtained educational level in 2012 from the Population Education Registry and replaced missing values with data from the

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survey. We retrieved information on income from the Income Statistics Registry. Equivalised disposable household income (considering both household income and household size) was calculated as an average for a 5-year period up to the year before disease onset (2008-2012) to capture income fluctuation over time. To account for income decline associated with retirement, we stratified income into older and younger than 65 years at date of diagnosis to divide income into quintiles.⁴⁰ Patients selfreported employment (employed, unemployed or outside the labour force) by the item 'Were you in employment, when you were diagnosed with heart disease? (yes/no)'. We combined this with information from the Registrybased Labour Force Statistics from 2012 to obtain information on missing values (n=194), and whether they were outside the labour force (retired).

Heart disease

We obtained information on type of incident heart disease (AF, HF, HVS and IHD) and acute versus planned hospitalisation from the NPR, and information on LVEF from the Danish Heart Registry (DHR) and the Danish Heart Failure Registry (DHFR). LVEF is an important prognostic factor and was used to indicate disease severity, with reduced LVEF defined as <40%.

Lifestyle factors

We used information on BMI from the DHR and smoking status from the DHR and DHFR for a 3-year period (2012–2014), because information on the two variables was relatively incomplete.

Medical history

We obtained somatic comorbidity from the NPR. A comorbidity score calculated for a 5-year period (up to disease onset) and classified into: none (score=0), mild (score=1) and severe (score≥2) was based on the Charlson Comorbidity Index.⁴¹ We identified prior anxiety and depression using diagnoses from the NPR and the Danish Psychiatric Central Research Registry (PCRR) along with dispensed prescriptions from the Danish National Prescription Registry (DNPR). We used this approach since many patients with anxiety and depression are managed in primary care only and do not have a diagnosis in hospital registries. PCRR has information on patients treated at psychiatric departments since 1970 and became an integrated part of the NPR in 1995, and the DNPR has information on all prescription drugs dispensed at community pharmacies since 1995. We identified diagnoses of anxiety (ICD-10: F40-F42; ICD-8: 300.09, 300.29, 300.39) and depression (ICD-10: F32, F33; ICD-8: 296.09, 296.29, 298.09, 300.49) from 1977. We identified dispensed prescriptions for drugs used in treating anxiety and depression (the Anatomical Therapeutic Chemical (ATC) Classifications: N06A excluding N06AX12 and N06AX21, N05B and N05C excluding N05CH01) from 1995. We chose ICD and ATC codes according to previous literature^{42 43} and in consultation with two experienced psychiatrists. We

grouped patients into current, recent, past or no anxiety or depression. Current anxiety or depression was defined as a diagnosis and/or >1 redeemed prescription within 90 days, and recent anxiety or depression from 90 days up to 1 year before heart disease onset. We could not differentiate between anxiety and depression, because N06A is used in treating both, and the variable indication for prescribing the drug in the DNPR is not mandatory.

Organisational factors

We obtained region (place of residence) from the CRS, and patients self-reported contact with the GP in the survey with the item 'Have you been in contact with your GP in relation to your heart disease? (yes/no)'.

Possible confounder

The time from diagnosis to questionnaire response was categorised into 10–14, 15–18 and 19–22 months.

Statistical analysis

We calculated descriptive statistics (percentages, means and SD) for the outcome variables and the potential predictors. Initially, we performed univariable logistic regression analysis. Multivariable logistic regression analysis was used to determine predictors associated with patient-reported lack of psychosocial healthcare using backwards elimination. We excluded statistically insignificant variables one by one-the most insignificant firstuntil all were statistically significant at a 5% significance level. We tested excluded variables one by one in the final model and included them if statistically significant. We calculated ORs with 95% CIs. Analysis were performed by using SAS V.9.4. We used multiple imputations by fully conditional specification (FCS) to impute values for item non-response generating 20 imputed data sets.⁴⁴ We chose this as the primary analysis, because item non-response was high for a few variables. We used the FCS because of the arbitrary missing data pattern with both categorical and continuous variables. The imputation model contained 42 variables: the outcome variables, potential predictors and auxiliary variables assumed to predict the missing values. We conducted three sensitivity analyses to evaluate the robustness of the results. First, we performed complete case analysis. Second, we excluded patients' responses of 'do not know' to reported lack of psychosocial healthcare. Finally, we analysed patient-reported lack of psychosocial healthcare as a continuous variable using linear regression. However, model assumptions evaluated by visually inspecting of residual plots and QQ-plots were not fulfilled. We also compared respondents and nonrespondents to examine whether the non-respondents deviated from the respondents.

Patient and public involvement

Patients were involved in the development of the survey as described in the section questionnaire-based survey.

RESULTS

We received eligible responses from 2496 patients (56%). An additional 533 returned the questionnaire but were excluded because they stated that they did not have heart disease in 2013 (online supplemental figure 3). Of the patients, 30% had AF, 11% HF, 16% HVS and 43% IHD. The mean age was 68.7 years (SD \pm 11), and 35% were women (table 2).

Prevalence of patient-reported psychosocial healthcare

A total of 40% reported lacking information on psychosocial aspects, ranging among the four types of heart disease from 29% for HVS to 56% for AF (table 3). Half (51%) the patients reported lacking psychosocial rehabilitation and support (41%–71%), and 32% reported lacking both types of psychosocial healthcare (19%– 51%). We observed minor differences between available and imputed cases.

Predictors of patient-reported psychosocial healthcare

The initial univariable logistic regression analysis found age, gender, cohabitation, employment, type of heart disease, prior anxiety or depression, region and no contact with GP to be associated with reporting lack of psychosocial healthcare. BMI and comorbidity were associated with lacking information on psychosocial aspects and lacking both types of psychosocial healthcare. Time from diagnosis to questionnaire response was associated with reporting lack of both types of psychosocial healthcare (online supplemental table 1).

The multivariable logistic regression analysis showed that patients who were older, were women, had AF, HF or IHD and had no contact with their GP more frequently reported lacking information on psychosocial aspects (figure 1). Patients who were older, were women, had AF, were outside the labour force, lived in the capital region and had no contact with their GP more frequently reported lacking psychosocial rehabilitation and support (figure 2), and patients who were older, were women, had AF, HF or IHD, had severe comorbidity, had recent or past anxiety or depression, lived in the capital region and had no contact with their GP more frequently reported lacking both types of psychosocial healthcare (figure 3). Cohabitation, BMI and time from diagnosis to questionnaire response were no longer associated with any of the outcomes.

The sensitivity analysis altogether confirmed the robustness of the results (online supplemental figures 4–11).

Comparison of respondents and non-respondents

Non-response was more likely among women, singles, patients with lower educational level and lower income groups and among current smokers. Patients with AF or HF, acute hospitalisation, reduced LVEF, severe comorbidity, prior anxiety or depression or from the capital region of Denmark were also over-represented in the non-response group (online supplemental table 2).

Table 2 Characteristics of t	Table 2 Characteristics of the participants				
	All, available data*	All, imputed data†			
Age, mean, years (SD)	68.7 (11.0)	68.7 (11.0)			
Gender, women, n (%)	880 (35.3)	(35.3)			
Ethnic background, Danish origin, n (%)	2357 (94.4)	(94.4)			
Cohabitation, n (%)	1817 (72.8)	(72.8)			
Educational level, n (%)					
Lower-secondary school	891 (35.8)	(35.9)			
Upper-secondary or vocational school	1036 (41.6)	(41.6)			
Higher education	561 (22.6)	(22.5)			
Missing	8				
Income quintiles‡, n (%)					
1. Lowest	499 (20.0)	(20.0)			
2	499 (20.0)	(20.0)			
3	498 (20.0)	(20.0)			
4	499 (20.0)	(20.0)			
5. Highest	498 (20.0)	(20.0)			
Missing	3				
Employment, n (%)					
Employed	612 (24.5)	(24.5)			
Unemployed	112 (4.5)	(4.5)			
Outside the labour force	1772 (71.0)	(71.0)			
BMI, n (%)					
Underweight	22 (1.3)	(2.0)			
Normal	558 (33.6)	(31.6)			
Overweight	715 (43.0)	(41.6)			
Obese	368 (22.1)	(24.8)			
Missing	833				
Smoking status, n (%)					
Never smoker	563 (33.1)	(34.0)			
Ex-smoker	754 (44.4)	(43.8)			
Current smoker	382 (22.5)	(22.2)			
Missing	797				
Type of heart disease, n (%)					
Atrial fibrillation	757 (30.3)	(30.3)			
Heart failure	265 (10.6)	(10.6)			
Heart valve surgery	391 (15.7)	(15.7)			
Ischaemic heart disease	1083 (43.4)	(43.4)			
Acute hospitalisation, n (%)	1282 (51.5)	(51.5)			
Missing	8				
LVEF ≤40%, n (%)	381 (28.2)	(30.9)			
Missing	1144				
Comorbidity, n (%)					
None (score=0)	1565 (62.7)	(62.7)			
Mild (score=1)	510 (20.4)	(20.4)			
		Continued			

Continued

Table 2 Continued		
	All, available data*	All, imputed data†
Severe (score≥2)	421 (16.9)	(16.9)
Prior anxiety or depression, n (%)		
None	1527 (61.2)	(61.2)
Past	487 (19.5)	(19.5)
Recent	140 (5.6)	(5.6)
Current	342 (13.7)	(13.7)
Region, n (%)		
Capital Region of Denmark	630 (25.2)	(25.2)
Central Denmark Region	568 (22.8)	(22.8)
North Denmark Region	262 (10.5)	(10.5)
Region of Southern Denmark	599 (24.0)	(24.0)
Region Zealand	437 (17.5)	(17.5)
Contact with GP, yes, n (%)	1918 (80.4)	(80.2)
Missing	110	
Time from diagnosis to questionnaire response Months§, n (%)		
10–14 months	844 (33.8)	(33.8)

10–14 months	844 (33.8)	(33.8)
15–18 months	773 (31.0)	(31.0)
19–22 months	879 (35.2)	(35.2)

When registry information on a few patients was missing in the year of interest, it was retrieved from the year before or the year after.

*The numbers of patients shown are the complete available information for each potential predictor.

†The numbers shown are the proportions (%) after multiple imputation was performed to estimate values for missing data. ‡The exact numbers of the income quintiles are not shown, because income was stratified into two age groups above and below 65 years before dividing them into quintiles. §Standard month=30 days.

BMI, body mass index; GP, general practitioner; LVEF, left ventricular ejection fraction.

DISCUSSION Main results

Patients with heart disease frequently report lack of psychosocial healthcare. A total of 32% reported lacking both information on psychosocial aspects and psychosocial rehabilitation and support, ranging among the four types of heart disease from 19% for HVS to 51% for AF. Type of heart disease most strongly predicted patient-reported lack of psychosocial healthcare, especially among patients with AF. Older age, female gender and no contact with GP also predicted patient-reported lack of psychosocial healthcare. Patients outside the labour force and living in the capital region more frequently reported lacking psychosocial rehabilitation and support, and patients with recent or past anxiety or depression and

severe comorbidities more frequently reported lacking both types of psychosocial healthcare.

Interpretation

According to guideline recommendations and to patients' needs, patients with heart disease should receive psychosocial healthcare. However, many patients reported not receiving any psychosocial healthcare. Although previous findings have identified challenges with the psychosocial aspect of patient care,¹⁶ ²⁴ ²⁷ the extent of the problem among patients with heart disease in Denmark is surprising, since psychosocial support has been part of the national clinical guidelines on cardiac rehabilitation for two decades,⁴⁵ and the involvement of patients is one of eight national goals for the healthcare sector.⁴⁶ The problem is emphasised by our conservative dichotomisation of patient-reported psychosocial healthcare into nothing versus something and that patients answered the questions 10-22 months after diagnosis, providing time for the healthcare system to deliver the care. It could be argued that not all patients should receive psychosocial healthcare but only those in need. However, our measure was developed based on what is important according to patients, and covered items relevant for all patients for example, 'Do you feel informed about the emotional reactions you may experience as a result of your disease?'.

Importantly, our results suggest that those who most need psychosocial healthcare are not those who report receiving it, since patients with prior anxiety or depression and with severe comorbidity more frequently reported lacking psychosocial healthcare. Moreover, older patients and women report worse mental health related to heart disease such as anxiety, depression and poor quality of life.^{79 47} Also, people being outside the labour force more frequently reported lacking psychosocial healthcare.

Type of heart disease most strongly predicted patientreported lack of psychosocial healthcare, especially among patients with AF. Recent studies have shown that psychosocial problems are frequent among patients with AF,⁷ and depression increase the risk of incident AF.⁴⁸ Thus, the results of our study call for special attention targeting patients with AF. The national clinical guidelines on cardiac rehabilitation covered HF, HVS and IHD and not AF when this study was conducted.³⁹ This may partly explain why AF was found to be the strongest predictor. However, the relatively large differences between patients with HF, HVS and IHD indicate that healthcare professionals' understanding of the patient groups' conditions and needs may also be an important aspect.

Our results indicate that GPs play a key role in ensuring psychosocial care. Similarly, a previous study concluded that screening for depression, although inadequate, seemed to be more frequent in general practice than at the hospital.³⁶

Current clinical guidelines in Denmark do not offer specific interventions or communication strategies for preventing and treating psychosocial risk factors, whereas the ESC guidelines are more comprehensive.^{1 39} However, Table 2

	Total	Atrial fibrillation	Heart failure	Heart valve surgery	Ischaemic heart disease	
	N (%)	n (%)	n (%)	n (%)	n (%)	
Patient-reported information on psychosocial aspects						
Nothing	829 (40.1)	338 (56.1)	89 (42.0)	93 (28.6)	309 (33.3)	
Something	1239 (59.9)	265 (44.0)	123 (58.0)	232 (71.4)	619 (66.7)	
Missing	428	154	53	66	155	
Nothing (imputed data)	(40.8)	(56.4)	(40.2)	(30.2)	(34.0)	
Patient-reported psychosocial rehabilitation and support						
Nothing	1078 (50.8)	444 (71.0)	100 (46.7)	146 (43.6)	388 (40.8)	
Something	1046 (49.3)	181 (29.0)	114 (53.3)	189 (56.4)	562 (59.2)	
Missing	372	132	51	56	133	
Nothing (imputed data)	(50.8)	(70.1)	(45.2)	(42.9)	(41.6)	
Both types of patient-reported psychosocial healthcare						
Nothing	615 (31.8)	285 (50.6)	62 (32.0)	58 (19.1)	210 (24.0)	
Something	1322 (68.3)	278 (49.4)	132 (68.0)	246 (80.9)	666 (76.0)	
Missing	559	194	71	87	207	
Nothing (imputed data)	(31.9)	(49.3)	(29.1)	(20.2)	(24.7)	

Nothing (score=0), something (score≥1).

the placement of responsibility and skills requirements for clinicians to provide psychosocial care are not addressed. Moreover, initiatives should be launched to facilitate implementation, such as training healthcare staff and students to provide psychosocial care.

Prevalence of patient-reported psychosocial healthcare

Patient experiences are subjective, and the predictors found could be influenced by differences in recall and in expectations, rather than what they received, even though measuring experiences rather than satisfaction has been suggested to reduce the influence of expectations.^{24 30} Depression and anxiety may for example, affect recall of being given psychosocial care. However, older patients have previously been found to be more satisfied with health services than younger patients, studies on gender and patient satisfaction are inconclusive,³¹ and there is no reason to believe that patients with for example, AF have higher expectations than others. Moreover, it is not straightforward to determine when patients have received psychosocial healthcare. Is it when clinicians perceive they have provided it, or when patients perceive

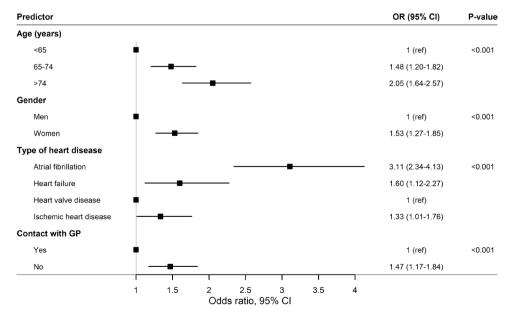


Figure 1 Multivariable logistic regression analysis, imputed data, for predictive factors of patient-reported lack of information on psychosocial aspects. GP, general practitioner.

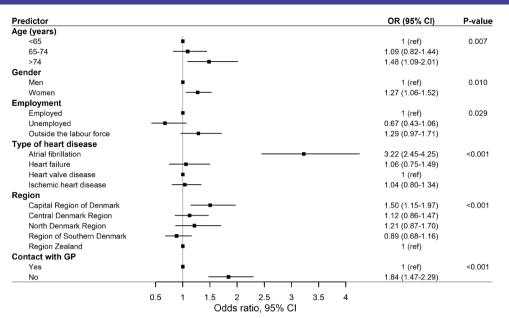


Figure 2 Multivariable logistic regression analysis, imputed data, for predictive factors of patient-reported lack of psychosocial rehabilitation and support. GP, general practitioner.

they have received it? There is not necessarily agreement between the two sources of information, emphasising the need to gather information from various sources. An overall goal must be to decrease discrepancy between patients' and clinicians' perceptions. Not least because psychosocial healthcare may only be effective if patients perceive receiving it. Future research should explore this possible discrepancy and how to overcome it. Importantly, enhancing patients' experiences is increasingly recognised as a legitimate independent goal for healthcare services, ²⁸ ²⁹ and good patient experiences are positively associated with clinical outcomes such as adherence to treatment and mortality.^{21 49–51}

Our study identified a low prevalence of patientreported psychosocial healthcare and subset of patients who more frequently report lack of psychosocial healthcare. Other studies, such as qualitative studies, are needed to provide insight on how to improve this important dimension of quality of care.

Strengths and limitations

To our knowledge this is the first large-scale study to evaluate heart patients' experiences with psychosocial healthcare from first contact with the healthcare system to the inpatient and outpatient treatment and rehabilitation in a nationwide population-based survey. This allowed

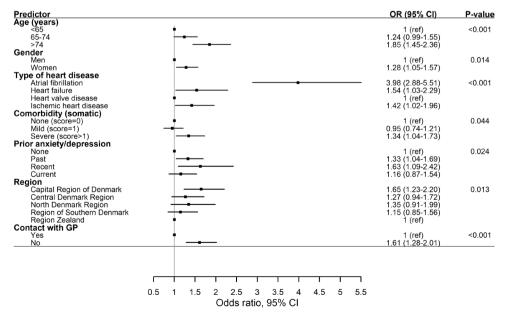


Figure 3 Multivariable logistic regression analysis, imputed data, for predictive factors of patient-reported lack of both information on psychosocial aspects and psychosocial rehabilitation and support. GP, general practitioner.

us to gain insight on the proportion who experience not receiving psychosocial healthcare throughout their patient journey across sectors. Strengths include the study design, with potential predictors measured before disease onset in a cohort of incident cases. Further, access to a large random sample of patients from the patient registry minimised selection bias. Access to potential predictors in registries limited recall bias.

Limitations should be considered. Since, there is no consensus on the definition of psychosocial healthcare, operationalising the concept and comparing with other studies are challenging,^{11 13 36} and our measure does not capture all aspects of the psychosocial healthcare patients may need. We focused on patient-reported psychosocial healthcare and developed the measure based on what patients perceive to be important for the quality of healthcare. In total 56% the invited patients completed the survey which is common in survey-based studies among patients. In our study register information about nonrespondents made it possible to consider the implications. The proportion reporting lack of psychosocial healthcare is likely to be even higher, because the identified predictors of patient-reported lack of psychosocial healthcare were over-represented in the non-response group. We used multiple imputations to avoid substantial loss of statistical power, ensure appropriate estimates of uncertainty and adjust for the bias complete case analysis otherwise could introduce due to item non-response.⁴⁴ A total of 533 respondents stated that they did not have heart disease. The mean positive predictive value of cardiovascular diagnoses in the NPR is 88% but ranges from 64% to 100%. Thus, even with a registry with generally high validity, some of the identified patients do not have the registered diagnosis or may not recognise their own condition as heart disease. The time from diagnosis to questionnaire response was 10-22 months, which could influence recall of psychosocial healthcare. There is, however, no indication of this since the time from diagnosis to questionnaire response was not statistically significant in the multivariable analysis. Finally, variables were limited to those accessible from the survey and registries, primarily containing patient-level information, but organisational factors and healthcare provider attributes may also be important. Previous studies have found no or limited organisational influence on patient experience.^{53 54} Women physicians address psychosocial issues significantly more than men,⁵⁵ and healthcare providers' attitudes towards psychosocial aspects of patient care and perceived lack of skills to deal with psychosocial concerns also seem to be important.⁵⁶ The results of this study may be translated to other western countries. The problem with patient-reported lack of psychosocial healthcare is though expected to be more pronounced in the USA where healthcare is not free and universal depending on health insurance.

CONCLUSIONS

The results revealed that many patients with heart disease reported lacking psychosocial healthcare. Importantly,

people who most need psychosocial healthcare, are not those who report receiving it. This calls for urgent action to translate guidelines into clinical practice that emphasises the importance of providing psychosocial healthcare to patients with heart disease.

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Competing interests None declared.

Patient and public involvement Patients and/or the public were involved in the design, or conduct, or reporting, or dissemination plans of this research. Refer to the Methods section for further details.

Patient consent for publication Not required.

Ethics approval The study was approved by the University of Southern Denmark no. 17/8592 (10.735). According to Danish law, this type of study does not require further formal ethic approval. Participants provided informed consent for participation by returning the questionnaire. The letter sent to patients together with the survey explained the study aim, assuring them that participation was voluntary and that the results would be anonymous.

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Data availability statement Data are available upon reasonable request. Data may be obtained from a third party and are not publicly available.

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