

## Patient Perception, Preference and Participation

## Supportive care needs in patients with cardiovascular disorders

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## ABSTRACT

**Objectives:** Unmet medical needs are a focus in cardiovascular disorder (CVD) research. However, few studies have investigated patients' perceived needs. The present study examined supportive care needs in patients with CVD and their relation to health characteristics.

**Methods:** In total 260 in-patients with CVD were consecutively assessed with the supportive care needs survey. Primarily, frequency and content of unmet needs were examined. Secondly, CVD-diagnoses were compared and correlations with risk factors, treatment characteristics, mood-state and quality of life were analyzed.

**Results:** Supportive care needs were indicated by 21% of all patients: unmet health information (37%) and psychological (23%) needs were most frequent. The number of unmet needs did not differ between most CVD-diagnoses. Unmet needs were not related to cardiac risk factors. However, treatment characteristics ( $r = .17-.23$ ,  $p < .01$ ), anxiety ( $r = .44-.71$ ,  $p < .01$ ), depression ( $r = .38-.63$ ,  $p < .01$ ), physical ( $r = .21-.47$ ,  $p < .01$ ) and mental ( $r = .29-.65$ ,  $p < .01$ ) quality of life were associated with unmet needs.

**Conclusions:** Supportive care needs are common in patients with CVD. They are based on patients' treatment characteristics, emotions and subjective well-being rather than on cardiac factors.

**Practice implications:** Needs assessments in patients with CVD could detect unmet needs, enhance patient education and communication and, therefore, effectively target patients' perceived needs and medical needs.

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## 1. Introduction

Recent epidemiological studies show declining mortality rates of cardiovascular disorders in western countries [1]. Despite major medical advances, however, the absolute number of treated patients increases due an aging population [2]. This fact makes cardiovascular disorders a health and economic burden, which is associated with loss of quality-adjusted life years and increasing health care costs [3]. There is, therefore, considerable need for cost-effective and patient-tailored disease management programs on the one hand and risk-population based prevention programs on the other.

However, effective disease management programs are difficult to implement [4–7]. A Major challenge for secondary prevention

programs could be the discrepancy between medical treatment advice (*as well as favorable treatment goals*) and patients' perceived illness related disability and their associated need for help. Supportive care needs is a new approach widely used in psycho-oncology which tries to capture this subjective burden of an illness "by directly measuring patients' own perceptions of their need for help on given issues as well as the magnitude of their desire for help in dealing with those needs" [p. 602, 8]. According to Bonevski et al. [9] needs assessments have three major advantages over other patient-reported-outcomes: (1) direct indication of needed resources, (2) quantifying unmet needs, and respectively allocating health resources, (3) identification of patients and subgroups with levels of need and consequently, need-targeted prevention and early intervention.

Research on supportive care needs in patients suffering from cancer has identified important, but also unresolved health-issues concerning emotional distress (e.g. fear of progression), health information (e.g. health self-management), physical and daily living (e.g. pain), patient care (e.g. treatment choices), and sexuality (e.g. changes in sexual feelings). Moreover, various

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studies have shown associations between these need-domains with psycho-social morbidity [10], satisfaction with health-care, symptom complaints [11,12] and quality of life [13–15].

Jones et al. [16] investigated whether a patient-centered process of supportive care can improve patient-clinician communication. Results indicated that this approach helps patients to reflect, to initiate a discussion and to get validation on their unmet needs. Patients felt encouraged to seek help and support and could focus clinicians' attention toward unmet needs. By enhancing patient-clinician communication, health care resources can be allocated to the issues patients themselves have identified as the most important. Moreover, in clinical practice, a comparison of perceived unmet needs with favorable medical treatment advice has the means to establish a treatment consensus. Ultimately, increased treatment adherence can reduce the health and economic burden of cardiovascular disorders.

To the best of our knowledge this is the first study to examine supportive care needs in patients with cardiovascular disorders. The primary aim was to characterize the quantity and content of unmet needs. As secondary aims, we compared the amount of needs across different cardiovascular disorders and examined associations between supportive care needs with risk factors, treatment characteristics, mood state and quality of life.

## 2. Methods

### 2.1. Study sample

Inpatients with any known cardiovascular disorder were screened for eligibility between the 15th September and 15th December 2010 on all wards except for the intensive care unit. Inclusion criteria were sufficient language skills, age greater than 18 years, and written informed consent as directed by the local Ethics Committee. Exclusion criteria were kept at a minimum to assess a representative sample of inpatients with cardiovascular disorders. Patients who were discharged early, those with cognitive deficits or, motor deficits, or symptomatic transitory psychotic syndrome were excluded.

### 2.2. Assessment

Patients were screened for eligibility if they were diagnosed with any cardiovascular disorder by an experienced cardiologist from the University Heart Center. Additionally, medical records were checked if the cardiovascular disorder was the primary diagnosis for current inpatient treatment. On average, on the 5th day ( $SD \pm 8$ ) of stay, patients filled out a questionnaire assessing their levels of unmet needs. In addition, patients answered questions on socio-demographic data, mood state, quality of life and the following risk factors: smoking, alcohol consumption and obesity. The following risk factors were assessed through medical records: hypertension, hyperlipidemia, diabetes, obesity, nicotine and alcohol abuse. To define treatment characteristics the way of referral, surgical procedures, medication and length of stay were also assessed. Additionally, we asked patients if they had ever been in psychotherapy.

### 2.3. Questionnaires

#### 2.3.1. Supportive care needs survey (SCNS-SF34) [8]

The SCNS-SF34 is a validated 34-item instrument which measures patients' perceived needs across a range of five domains: psychological (emotions and coping), health system and information (treatment center and information about the disease), physical and daily living (coping with physical symptoms, side effects, performing usual physical tasks), patient care (health care providers showing sensitivity to physical and emotional needs, privacy and choice) and

sexuality needs (sexual relationships). Across various studies in patients with cancer the SCNS-SF34 has shown high internal consistency (Cronbach's alpha: 0.86–0.96) and demonstrated convergent validity with other measures of psychosocial well-being. The questionnaire was adapted to cardiovascular disorder by replacing the term cancer with cardiovascular disorder and rephrasing single items (e.g. "fear of cancer spreading" into "fear of cardiovascular disorder progressing"). To quantify supportive care needs, patients are asked to answer on a five-point likert scale ('no need', 'need, but satisfied', 'low need', 'moderate need', 'high need'); to identify patients with unmet needs answers are dichotomized in "no need" ('no need', 'need, but satisfied') versus "unmet need" ('low need', 'moderate need', 'high need'). Additionally, to assess overall need sum scales can be calculated ranging from 0 to 100.

#### 2.3.2. Short-Form 12 (SF-12) [17,18]

The SF-12 is a reliable and well-validated tool to measure quality of life in multiple groups of patients and several recent studies have demonstrated its validity in cardiovascular research [19,20]. The 12 items assess both physical and mental health, which are represented by the physical component summary score and the mental component summary score. These scores were calculated according to the German manual (for detailed information see [21]).

#### 2.3.3. Hospital Anxiety and Depression Scale (HADS) [22]

The HADS is a 14-item self-report measure and was developed to screen for emotional distress in medical patients [23,24]. It has been shown to be a reliable and well-validated scale in various studies in patients with cardiovascular disorders [25,26]. Two sum scores are calculated for anxiety and depressive symptoms. Total scores range from 0 to 21, where a score between 0 and 7 is in the 'normal' range, a score between 8 and 10 is suggestive of a mild mood disorder and a score of 11 or more indicates the presence of a moderate or severe mood disorder.

### 2.4. Statistical analysis

Primarily, in an analogous fashion to previous research on supportive care needs, descriptive analyses were conducted examining the quantity, distribution, frequency and contents of unmet needs. As secondary analyses, we examined associations between supportive care needs domains and important health markers. First, odds-ratios were calculated to compare levels of supportive care needs between primary cardiovascular diagnoses. Second, bi-variate correlational analyses testing associations between supportive care needs with risk factors, medical care use, mood-state and quality of life were calculated. Sample size estimation was based on other studies examining the frequency and content of supportive care needs [8]. For secondary explorative analyses, a power-analysis was carried out to detect small to medium effects (Pearson's  $r = .15$ ) while calculating bivariate correlational analyses (with power  $\beta = .80$  and significance level  $\alpha = .05$ ). Based on these estimations and incorporating a conservative attrition rate of 15% we determined that a sample size of  $N = 300$  patients would be appropriate. Single missing values were estimated and completed using multiple-imputation analysis according to recommendations [27]. All analyses were performed using SPSS for windows version 18.0 (SPSS Inc., Chicago, USA).

## 3. Results

### 3.1. Sample

A total of 333 patients with any cardiovascular disorder were screened for eligibility (see Fig. 1). Of these, 260 patients gave

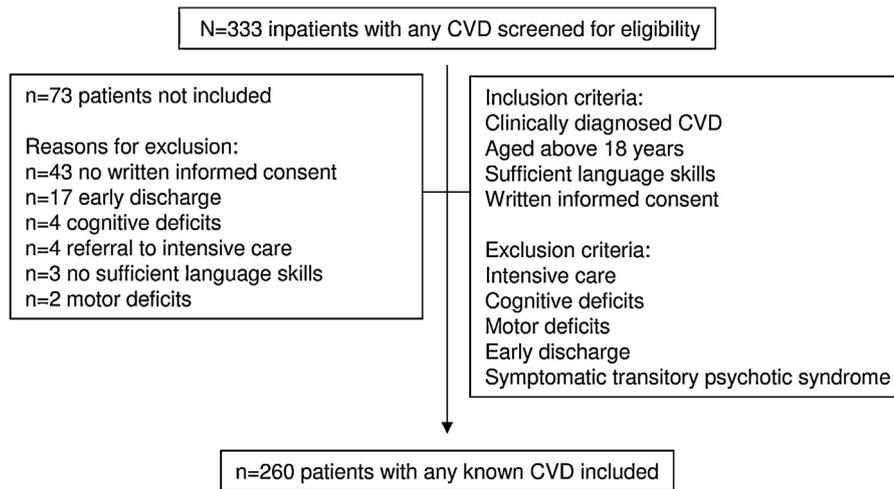


Fig. 1.

written informed consent as directed by the local Ethics Committee and were included into analyses. Table 1 summarizes the patients' characteristics. Most patients were male (70%), on average 63 years old, not living alone (76%) and still working (63%). On average they spent seven days in hospital with nearly half of them (47%) received invasive procedures. Most came electively (70%). Still, more than half of the sample (52%) reported a physical quality of life below average. Almost every fourth patient (23%) reported a mental quality of life below average with 38% experiencing anxious and 26% having depressive symptoms. Nearly every fifth patient (18%) reported having received psychotherapy. In terms of risk factors, patients' self-reports differed from physicians' ratings: 23% were diagnosed with nicotine abuse, but 73% of the patients indicated themselves as being a current or past smoker. In contrast, 2% were diagnosed with alcohol abuse, 12% reported drinking alcohol on daily occasion. Finally, 12% were also diagnosed as obese, however, nearly twice as many reported a body mass index above 30.

### 3.2. Care Needs Survey – Psychometric properties

For all sum scales internal consistency (Cronbach's alpha) was indicated as substantial, as follows: psychological alpha = .94, health information alpha = .96, daily living alpha = .97, patient care alpha = .88 and sexuality alpha = .80. Intercorrelations between subscales were moderate and ranged from  $r = .49$  to  $r = .73$  (for all:  $p < .001$ ).

### 3.3. Supportive Care Needs Survey – descriptive analysis

Frequency analysis indicated that on average 21% of all patients indicated unmet supportive care needs. Concerning the need domains, 37% of all patients reported unmet health information needs, 23% psychological needs, 14% needs concerning daily living, 11% patient care needs and 18% needs concerning sexuality. Means and standard deviation errors of need domains are shown in Table 2.

Item content analysis showed that there were five supportive care needs indicated by over half of the patients. These needs mainly comprised of health information needs concerning contact to hospital staff, coping with disease, diagnostic information, treatment benefits and side-effects. However, more than 50% of the patients also indicated unmet psychological needs to deal with the fear of disease progression (see Table 3).

### 3.4. Supportive Care Needs Survey – differences in primary diagnosis

Fig. 2 displays odds-ratios (OR) with confidence intervals (CI) to compare need domains in patients with different primary cardiovascular disorders including chronic heart failure, coronary heart disease, heart valve diseases and heart arrhythmias. Patients with chronic heart failure reported 2.95 times greater needs concerning daily living (OR = 2.95, CI = 1.39–6.25,  $p = .005$ ) and tended to indicate 1.62 times greater psychological needs (OR = 1.62, CI = .77–3.41,  $p = .20$ ). In contrast patients with heart arrhythmias showed 2.32 times lower needs in daily living compared to patients with other primary cardiovascular disorders (OR = 2.32, CI = 1.23–4.36,  $p = .009$ ). Most ORs of the comparisons between patients with different primary cardiovascular disorders ranged around one indicating that there were no significant differences in supportive care needs between these groups of patients.

### 3.5. Supportive Care Needs Survey – correlational analysis

No correlations between socio-demographic data and supportive care needs were evident, except a low correlation with years of education ( $r = -.14$ ,  $p < .05$ ) suggesting that higher education was related to lower daily needs. In terms of cardiovascular risk factors, associations with need-domains were relatively low: non-smokers tended to report lower psychological ( $r = .12$ ,  $p < .05$ ) and sexual needs ( $r = .12$ ,  $p < .05$ ); patients with diabetes reported higher needs concerning daily living ( $r = .16$ ,  $p < .05$ ) and patient-care support ( $r = .12$ ,  $p < .05$ ); the more diagnoses the more daily living needs ( $r = .15$ ,  $p < .05$ ) and sexuality needs ( $r = .12$ ,  $p < .05$ ) were reported. Patients with daily alcohol consumption indicated fewer needs concerning daily living ( $r = .13$ ,  $p < .05$ ) and patient-care support ( $r = .12$ ,  $p < .05$ ). Several correlations with variables defining treatment characteristics were indicated (see Table 4), showing significant associations to needs concerning daily living ( $r = .17$ –.23, all  $p < .01$ ) but also psychological needs ( $r = .14$ –.30, all  $p < .01$ ). Results indicated strong associations between unmet needs and contact to psychotherapy: patients who had been in psychotherapy reported less unmet needs across all supportive care need domains ( $r = .17$ –.30, all  $p < .01$ ).

Strong associations between supportive care needs mood state and quality of life were shown (see Table 5): higher scores across all need-domains related with higher level of depression ( $r = .38$ –.63, all  $p < .01$ ) and anxiety ( $r = .44$ –.71, all  $p < .01$ ), but

**Table 1**  
Characteristics of the study sample.

Variable	Mean ± SD/percentage (Nr)
<b>Demographics</b>	
Age	62.6 ± 12
Male gender	70% (184)
Years of education	14.5 ± 2.8
Living alone	24% (62)
Not working	37% (96)
<b>Primary diagnosis</b>	
Coronary heart disease	18% (47)
Chronic heart failure	12% (33)
Heart valve disease	10% (27)
Heart arrhythmia	39% (100)
Peripheral arterial disease	4% (9)
Other CVD diagnosis	10% (27)
Other non CVD diagnosis	6% (15)
<b>Risk factors – physician-rated</b>	
Hyperlipidemia	30% (77)
Diabetes	13% (31)
Hypertension	60% (155)
Adiposity	12% (31)
Alcohol abuse	2% (6)
Nicotine abuse	23% (60)
Nr. of comorbid CVD	1.2 ± 1.4
<b>Risk factors – self-rated</b>	
<b>Smoker</b>	
Yes	15% (38)
Yes, in the past	58% (151)
No, never	26% (68)
Daily alcohol use	12% (31)
Body mass index >30	22% (57)
<b>Treatment characteristics</b>	
<b>Referral</b>	
Elective	70% (182)
Emergency	20% (53)
From other hospital unit	10% (25)
Invasive procedures	47% (124)
Nr. of drugs	6.7 ± 3.2
Length of stay	7.3 ± 10.9
Ever in psychotherapy	18% (47)
<b>Quality of Life</b>	
<b>Physical Component Summary</b>	
Below average	52% (135)
In average	48% (124)
Above average	<1% (1)
<b>Mental Component Summary</b>	
Below average	23% (60)
In average	70% (182)
Above average	7% (18)
<b>Mood State</b>	
<b>Anxiety</b>	
Moderate	25% (65)
Severe	13% (35)
<b>Depression</b>	
Moderate	18% (47)
Severe	8% (22)

lower scores on physical ( $r = -.21$  to  $-.47$ , all  $p < .01$ ) and mental ( $r = .29$ – $.65$ , all  $p < .01$ ) quality of life. In other words, patients reporting unmet needs were more likely to report a lower quality of life and worse mood state.

**Table 2**  
Patients reporting low, moderate or high supportive care needs.

Domain	Means ± SDe	Low need	Moderate need	High need
Health information	36.8 ± 1.9	23% (60)	9% (23)	5% (14)
Psychological	30.7 ± 1.6	15% (40)	7% (18)	<1% (1)
Daily living	23.6 ± 1.4	10% (27)	3% (7)	<1% (1)
Patient care	20.6 ± 1.5	6% (15)	3% (9)	2% (5)
Sexuality	21.6 ± 1.5	12% (30)	5% (13)	1% (3)

## 4. Discussion and conclusion

### 4.1. Discussion

The treatment of cardiovascular disorders mainly aims to reduce and control medical risk factors. Integrating patients' perceptions of need for help into patient-consultation could enhance achievement of these treatment goals. To the best of our knowledge, this is the first study in patients with cardiovascular disorders that has examined perceived supportive care needs and quantified, detected and characterized unmet needs. Moreover, associations between unmet needs with risk factors, treatment characteristics, mood state and quality of life were shown. Based on these findings, future research and clinical implications can be derived.

On average every fifth patient treated for a cardiovascular disorder reported unmet supportive care needs. Similar rates have been shown for inpatients suffering from cancer [10,28]. Patients with cardiovascular disorders showed a broad spectrum of supportive care needs. Needs concerning health information and psychological support were the most frequent. Less frequently patients reported unmet needs concerning daily living, patient care and sexuality. It is possible, however, that the need profile of this patient population was influenced by the current inpatient treatment. Routinely, patients receive their health information at discharge and, therefore, unmet health information needs might decrease after discharge. In the current sample 38% of patients indicated anxious and 26% showed depressive symptoms. These negative emotional states can influence information processing [29]. As follows, this could influence perceived unmet health information needs. Increased rates of depression and anxiety might be the reason why the second most frequent perceived needs were psychological needs. Negative emotional states might decrease after discharge and so psychological needs might also decrease. Patients who had ever been in psychotherapy reported lower unmet needs. As follows, it would be worth investigating whether patients benefit from a psychological treatment approach based on their psychological need profile. However, future studies should firstly investigate if this need profile can be replicated. Even more importantly, the supportive care need profile of outpatients should be examined, as these patients may rather focus on unmet needs concerning their day-to-day ability to cope with cardiovascular disorders.

So far, studies directly comparing the amount of unmet needs between different diseases are lacking. Interestingly, results from this study showed, that unmet needs did not differ between most primary diagnoses. Similar results have been reported for patients with different tumor diagnoses [30]. Still, it must be noted that patients with chronic heart failure reported higher needs concerning daily living compared to patients with other cardiovascular disorders. This might be due to greater symptom distress associated with chronic heart failure (e.g. dyspnea oedemas, fatigue). In contrast, patients with heart arrhythmias were less likely to indicate that they had unmet needs concerning daily living. Heart arrhythmias occur spontaneously and the associated symptoms might not interfere with daily living. Thus, these patients might report less need for help with their daily routine.

Interestingly, unmet needs were not related to objective health status (e.g. diagnosis, comorbidities) and associations with established risk factors (e.g. smoking, hypertension, diabetes) were marginal. Patients reporting unmet needs, however, showed specific treatment characteristics: they were more likely to be referred by emergency, stay longer in hospital, have more medications, and receive surgical procedures. Furthermore, these patients with unmet needs indicated a worse quality of life, as well as higher depression and anxiety scores. The latter result is a consistent finding in patients with cancer [12,31,32].

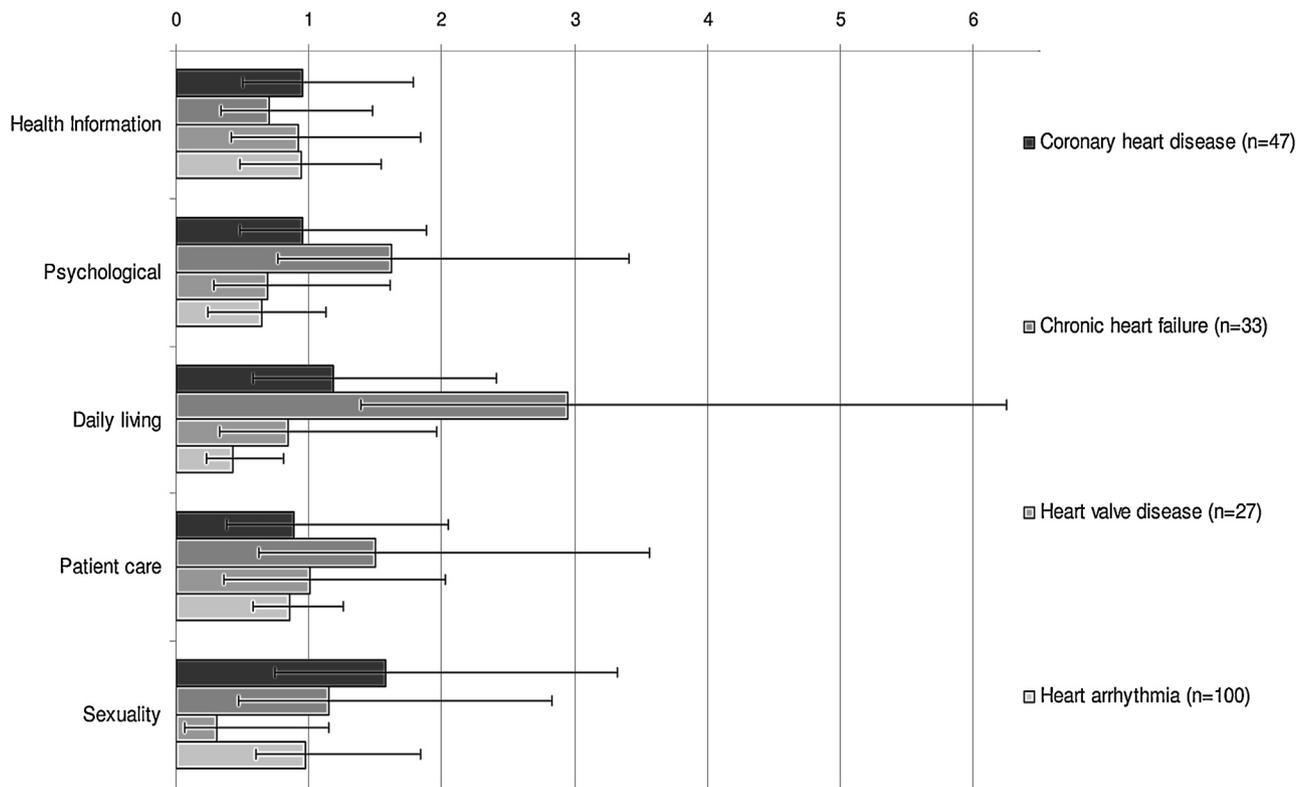


Fig. 2.

Taken together, these results suggest that unmet supportive care needs are based on patients' subjective experience with their cardiovascular disorder rather than on medical health status or cardiac risk factors. Strong associations between unmet needs with decreased quality of life and increased emotional distress underpin this assumption. Future studies should longitudinally investigate whether perceived health burden is influenced by unmet needs. Recent interventional trials targeting supportive care needs in patients with cancer did not find an effect on quality of life and emotional well-being [33,34]. Results from this study suggest that treatment characteristics are related to supportive care needs. Focusing unmet needs could help to meet patients specific treatment characteristics. Even more, integrating a needs

assessment into patient-consultation could have the means to allocate health resources to those patients most needing them, thus, reducing health burden and health care costs. But before testing these hypotheses, future studies should longitudinally investigate associations between supportive care needs with treatment characteristics, allocation of health resources and health care cost.

As Jones et al. [16] have shown, a supportive care needs approach can enhance patient-clinician communication. Patients whose unmet needs are not considered in medical treatment may focus on alternative therapies and might be less motivated to focus on medical risk factors (e.g. hypertension). By applying a supportive care needs assessment, clinicians could easily detect

**Table 3**  
Supportive care needs indicated by at least 50% of patients with CVD.

Item	Domain
Having one member of hospital staff with whom you can talk to about all aspects of your condition, treatment and follow-up.	Health information
Being informed about things you can do to help yourself to get well.	Health information
Being adequately informed about the benefits and side-effects of treatments before you choose to have them.	Health information
Being given explanations of those tests for which you would like explanations.	Health information
Fears about the progression of the disease.	Psychological

**Table 4**  
Correlations between supportive care needs and treatment characteristics.

Variable	Supportive care need domains				
	Psychological	Health information	Daily living	Patient care	Sexuality
Emergency referral	.11	.03	.17**	.08	.03
Invasive procedure	.06	-.04	.17**	.03	-.01
Nr. of drugs	.17**	.09	-.26**	.14*	.19**
Length of stay	.14*	.04	.28**	.08	.07
Ever in psychotherapy	-.30**	-.17**	-.23**	-.26**	-.21**

\* Significant at  $p < .05$ .

\*\* Significant at  $p < .01$ .

**Table 5**

Correlations between supportive care needs, mood state and quality of life.

Variable	Supportive care need domains				
	Psychological	Health information	Daily living	Patient care	Sexuality
Quality of life					
Physical component	-.27*	-.21*	-.47*	-.29*	-.27*
Mental component	-.65*	-.29*	-.60*	-.42*	-.46*
Mood state					
Depression	.60*	.38*	.63*	.47*	.41*
Anxiety	.71*	.44*	.58*	.51*	.46*

\* Significant at  $p < .01$ .

unmet needs and patients could get validation for their subjective need for help. In turn, treatment goals could be established in accordance with the patient. Banegas et al. [4] conclude that about one third of patients that are treated for a cardiac risk factor remain at high risk for developing a cardiovascular disorder. In a multicenter study they showed that of 7641 patients treated for cardiovascular risk factors only 39% had sufficient blood pressure control, 41% had their cholesterol controlled and only 37% reached their insulin control target. Moreover, referral, enrolment, and completion rates of secondary prevention programs could be optimized [5,6]. In clinical routine, a supportive care needs approach could enhance patient-tailored disease management programs to reduce under-controlled risk factors. It would be worth investigating whether such a treatment approach could increase treatment adherence in patients with cardiovascular disorders.

Few shortcomings of the current study must be mentioned: our sample consisted of consecutively assessed patients treated for any cardiovascular disorder in a university medical center. As unmet supportive care needs were not related to diagnoses and risk factors, we would not expect community-hospital patients to differ in supportive care needs from our sample. Still, it must be noted that results only apply for inpatients and may not necessarily apply to outpatients with cardiovascular disorders. We cannot rule out that results might be influenced by other variables (such as gender, education, or income). That is why replications of this study with larger sample sizes are needed to estimate the prevalence to unmet needs and compare our findings with other patient groups suffering from cardiovascular disorders. In terms of psychometric properties, the Supportive Care Needs Survey yielded good internal consistencies across all subscales and moderate inter-correlations indicated divergent internal validity between subscales. Thus, this survey is a reliable instrument to assess perceived supportive care needs in patients with cardiovascular disorders. Still, it must be noted that this is the first study evaluating this survey in this patient group and further validation is clearly needed.

#### 4.2. Conclusion

Firstly, this study demonstrated that patients with cardiovascular disorders report unmet supportive care needs. These needs mainly comprised health information and psychological needs. Unmet needs for help were related to subjective well-being and treatment characteristics, but not to health status or medical risk factors. A supportive care needs assessment could be a valuable approach to improve patient–clinician communication, especially as cost-effective and patient-tailored disease management programs are needed to sufficiently target treatment goals in patients with cardiovascular disorders.

#### 4.3. Practice Implications

Despite the fact that patients treated in hospital have direct contact to health care providers five unmet needs were indicated by more than half of the patients: (1) hospital staff member with

who they can discuss all aspects of their illness, treatment and follow-up, (2) information about illness self-management, (3) information about treatment benefits and side-effects, (4) diagnostic information about medical procedures, and (5) psychological help to deal with the fear of disease progression. These five supportive care needs could be directly addressed when consulting patients with cardiovascular disorders.

#### Conflict of interests

The authors declare that there is no conflict of interest.

#### Contributors

SK, KZ and KHS designed the study. MSK and SK collected data and studied the patients. SK conducted the literature searches and analyses, undertook the statistical analysis and wrote the first draft of the manuscript. All authors contributed to and have approved the final manuscript.

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