scientific reports

Check for updates

OPEN

Dimensional structure of the Brief Illness Perception Questionnaire and Association with adverse childhood experiences in patients with an implantable cardioverter-defibrillator

Marc Dörner[1,2]✉, Roland von Känel[1], Aju P. Pazhenkottil[1,3], Rahel Altwegg[1], Noelle König[1], Ladina Nager[1], Veronica Attanasio[1], Lisa Guth[1], Sina Zirngast[1], Anna Menzi[1], Claudia Zuccarella-Hackl[1] & Mary Princip[1]

Illness perceptions (IP), as measured by the Brief Illness Perception Questionnaire (BIPQ), and adverse childhood experiences (ACE) have been shown to affect the physical and psychological well-being in different patient populations. However, little is known about IP and ACE in patients with an implantable cardioverter-defibrillator (ICD). Our objectives were to investigate the dimensional structure and to evaluate correlates of the BIPQ in ICD patients. 423 patients with an ICD were prospectively recruited. We conducted a principal component analysis to determine the dimensional structure of the BIPQ. Associations between ACE, other sociodemographic and clinical variables, and IP were analysed using a multivariable linear regression. We identified a two-factor structure (I = Consequences, II = Control) of the BIPQ. Among others, a higher number of ICD shocks in the past (0.21, 95% CI = 0.01–0.41, *p* = 0.036), low physical activity (-2.16, 95% CI = -4.37 to -0.37, *p* = 0.045), more frequent ACE (0.56, 95% CI = 0.08–1.22, *p* = 0.030), ICD shock-related concerns (0.75, 95% CI 0.62–0.89, *p* < 0.001), and primary ICD indication (-2.29, 95% CI -4.47 to -0.11, *p* = 0.039) were significantly associated with more threatening IP. The identification of those variables might lead to more precise interventions targeting maladaptive IP in this vulnerable patient population.

Keywords Adverse childhood experiences, Implantable cardioverter-defibrillator, Illness perception, ICD shocks, Physical activity, Dimensional structure of the Brief Illness Perception Questionnaire

Life-threatening conditions of the cardiovascular system, such as ventricular arrhythmias, cardiac arrest, or sudden cardiac death, can be treated and prevented by an implantable cardioverter-defibrillator (ICD) through anti-tachycardia pacing or shocks. Despite the positive value for the physical health of patients, an ICD implantation and therapy have been associated with higher levels of psychological distress, i.e., depression, anxiety, or post-traumatic stress disorder symptoms, compared to the general population[1–3]. Moreover, psychological distress in patients with an ICD has been linked to increased mortality rates[4]. Previous studies also found that patients with an ICD suffer from a reduced quality of life and worse emotional functioning[5].

Additionally, a recent study suggested that ICD patients' illness perceptions (IP) may play an important role for their well-being. This study analysed various variables, including sociodemographic, clinical, and psychological characteristics. It concluded that female sex, poor health status, anxiety, depression, negative affectivity, and poor ICD acceptance were significant correlates of threatening IP[6]. However, this study did not include information about ICD shocks, physical activity, or other possible variables of interest, which precludes

[1]Department of Consultation-Liaison-Psychiatry and Psychosomatic Medicine, University Hospital Zurich, University of Zurich, 8091 Zurich, Switzerland. [2]German Center for Neurodegenerative Diseases (DZNE) within the Helmholtz Association, 39120 Magdeburg, Germany. [3]Cardiac Imaging, Department of Nuclear Medicine, University Hospital Zurich, University of Zurich, 8091 Zurich, Switzerland. ✉email: marc.doerner@usz.ch

more (disease-)specific assumptions. In particular, ICD patients often experience fear of triggering shocks with physical exercise, and thus they may have a tendency to avoid it. Interestingly, another study concluded that IP may contribute even more to psychological distress (e.g. anxiety or depression) than sociodemographic aspects and functional status in patients with cardiovascular disease (CVD)[7]. A third study that examined patient-reported outcomes in adults with congenital heart disease (including ICD patients) revealed higher IP scores for patients with heart failure compared to those with no current or past episode of heart failure[8].

IP are emotional and cognitive representations of health threats, and reflect patients' own beliefs about their illness. In general, there are five dimensions of the cognitive representations of IP: (1) beliefs about causes of the illness, i.e., ideas about its origin; (2) beliefs about consequences or the impact of the illness on life domains; (3) beliefs about the timeline, i.e., ideas about the duration of the illness; (4) beliefs about control of the illness or ideas about treatment and recovery; (5) and finally beliefs about identity or ideas of symptoms of the illness. On the other hand, emotional representations of IP comprise negative affects, such as fear or anger[9,10].

Still, although a few studies indicated the relevance of IP for the psychological well-being of patients with CVD or an ICD[6–8], little is known about the potential link between adverse childhood experiences (ACE) and IP in ICD patients. ACE are common in the general population, and consist of a broad spectrum of traumatic and distressful events before the age of 18, including sexual or physical abuse, household dysfunction, and neglect[11–14]. Of note, ACE have been demonstrated to predict detrimental health outcomes and an increased risk for the development of a mental or substance use disorder[15]. Furthermore, previous studies showed that ACE are also related to the emergence of chronic physical diseases, such as CVD, and its associated risk factors (e.g. arterial hypertension, diabetes, smoking)[16].

The Brief Illness Perception Questionnaire (BIPQ) is an established instrument to measure IP, and has been applied in several populations with different illnesses, varying by age or language[17]. However, data on its dimensional structure and psychometric qualities in ICD patients are scarce[6].

In this context, the objectives of the current study were (1) to explore the dimensional structure of IP as measured by the BIPQ in an ICD population and (2) to compare our findings to a previous study[6], and, as a novelty, (3) to investigate further variables which might be linked to threatening IP, such as ACE, the number of ICD shocks after ICD implantation, or physical activity.

Methods

Setting and sample

In this national single-centre cross-sectional study, 969 patients with an ICD or an implantable device with ICD-function (cardiac resynchronisation therapy with defibrillator option (CRT-D)) were recruited at their half-yearly routine check-up at the Cardiac Arrhythmia Division (Department of Cardiology) at the University Hospital Zurich between February 2020 and March 2023. Consequently, 650 patients met the inclusion criteria for participation in the study, i.e., having an ICD or CRT-D, an age between 18 and 80 years, sufficient German language skills, and a consent for participation in the study. Of those participants, 423 returned self-report questionnaires regarding psychological variables, sociodemographic, medical-related variables and ICD concerns. Obtaining permission to use the study's questionnaires was not necessary since there were no copyright issues. All participants provided informed consent. Participants were not exposed to any other burden than filling out self-report questionnaires, which does not pose a risk to patients. Since all participants were able to fully decide or consent to study participation, our participants did not have any legal representatives or relatives who had to consent on behalf of the patients. The study was approved by the Cantonal Ethics Committee of Zurich (no. 2019 – 01948, 12/2019).

Measurements

Brief Illness Perception Questionnaire

The BIPQ is a measure to evaluate emotional and cognitive representations of illness. Cognitive illness representations are assessed via five items, namely consequences ("How much does your illness affect your life?"), timeline ("How long do you think your illness will continue?"), personal control ("How much control do you feel you have over your illness?"), treatment control ("How much do you feel your treatment can help your illness?"), and identity ("How much do you experience symptoms from your illness?"). Emotional illness representations consist of two items, i.e., concerns ("How concerned are you about your illness?"), and emotions ("How much does your illness affect you emotionally?"). One item measures illness comprehensibility ("How well do you think you understand your illness?"). Each of its eight items is scored between 0 and 10 points, concluding in a total sum score of 80 points at maximum. Item 3 (personal control), item 4 (treatment control), and item 7 (understanding) had to be recoded due to reversed scoring. Higher scores indicate a higher perceived threat with regard to the illness[17]. Participants with a cut-off score of ≥ 42 points were classified as having at least a moderate threatening view of their illness[6,17]. The ninth item is an open-ended question which asks participants to name the three most important causal factors of their illness. In the current analysis, we did not include this item.

Adverse childhood experiences questionnaire

Adverse or traumatic experiences, i.e., childhood abuse, household dysfunction, and neglect, that an individual had before the age of 18 were measured by the ACE questionnaire (ACE-Q). The ACE-Q is a 10-item measure, and it is calculated as the sum of all "yes" answers (total score 0 to 10 points). Higher scores suggest a higher risk for mental, social, and other well-being problems[12]. Reliability testing indicated that Cronbach's alpha of the ACE-Q was 0.71.

ICD concerns questionnaire

ICD shock-related concerns were assessed using the eight-item ICD Concerns Questionnaire (ICDC). The ICDC measures the number and severity of patient concerns related to the ICD on a five-item Likert scale. This questionnaire has been found to be valid and reliable in multiple populations[18].

Statistical procedures

For statistical analysis, we used IBM SSPSS Statistics for Windows, Version 29 (Armonk, NY: IBM Corp). To describe patient characteristics, mean values, standard deviation, and relative and absolute distributions were calculated. An unpaired t-test was used to compare normally distributed continuous variables, and a chi-square test to compare categorical variables. A principal component analysis (PCA) was carried out for the determination of the factor structure of the BIPQ, and we performed a Bartlett's test of sphericity and the Kaiser-Meyer-Olkin measure of sampling adequacy (KMO-index) to evaluate if our data met the assumptions for PCA. We identified the number of factors to extract based on scree plot and eigenvalues. Internal consistency of the BIPQ was calculated via Cronbach's alpha. To investigate associations between the BIPQ scores (total and subscale score) as dependent variables, and ACE (ACE-Q total score) as an independent variable, we conducted a multivariable linear regression analysis. Further covariates were the continuous variables age, the number of ICD shocks after ICD implantation, and ICD shock-related concerns (ICDC total score); the categorical binary variables sex, past myocardial infarction, current smoking, use of alcohol, employment status (full or part time vs. unemployed or retired), marital status (married vs. divorced, widowed, or single), regular physical activity (question: "Do you exercise regularly that causes you to sweat?"), hospitalisation and/or cardiac rehabilitation after ICD implantation, ICD indication (primary vs. secondary); and the ordinal variables educational level, and heart failure on the basis of the left ventricular ejection fraction (LVEF), which has been divided into three subcategories: normal or preserved LVEF (≥ 50%), moderately reduced LVEF (41–49%), and reduced LVEF (≤ 40%)[19]. Collinearity statistics did not imply any issues of multicollinearity (variance inflation factor < 2.5 and tolerance > 0.4[20]), , unless otherwise noted. Significance level (two-sided p-value) was set at $p < 0.05$ and adjusted for multiple comparisons by post-hoc Bonferroni correction.

Results

Sample

Sociodemographic, clinical and lifestyle characteristics of the final study sample, stratified by IP (BIPQ < 42 vs. ≥ 42 points), and the amount of missing data for each variable are illustrated in Tables 1 and 2. 29.55% ($n = 125$) of all participants had at least a moderate threatening view of their illness, and 28.35% ($n = 110$) experienced at least one ICD shock in the past. Participants with a more threatening IP (defined by BIPQ ≥ 42 points) were more likely to be younger, to be unemployed, to have experienced more ICD shocks after ICD implantation, to have a reduced LVEF (≤ 40%), to be less physically active, to have participated more often in cardiac rehabilitation after ICD implantation, to have more ACE and ICD shock-related concerns. Of note, women had significantly higher ICD shock-related concerns than men (ICDC total score mean 9.5 points ± 8.2 vs. 7.1 points ± 7.6, $p = 0.007$).

	Total sample ($n = 423$)	BIPQ < 42 ($n = 298$)	BIPQ ≥ 42 ($n = 125$)	*p*-value ($p < 0.05$) group analysis	*p*-value subgroup analysis
Age (y), mean (SD)	57.7 (13.9)	58.6 (13.9)	55.4 (13.9)	**0.029**	
Female, n (%)	103 (24.4%)	65 (21.8%)	38 (30.4%)	0.054	
Educational level	n = 416	n = 293	n = 123		p < 0.00625
Lower than completed apprenticeship or equivalent, n (%)	17 (4.1%)	10 (3.4%)	7 (5.6%)		0.284
Completed apprenticeship or equivalent, n (%)	234 (56.2%)	164 (55.9%)	70 (56.0%)	0.705	0.86
High-school diploma or equivalent, n (%)	62 (14.9%)	44 (15.0%)	18 (14.4%)		0.92
University degree, n (%)	103 (24.7%)	75 (25.5%)	28 (22.7%)		0.541
Employment status	n = 418	n = 295	n = 123		p < 0.00625
Full time, n (%)	120 (28.7%)	92 (31.1%)	28 (22.7%)		0.082
Part time, n (%)	76 (18.1%)	53 (17.9%)	23 (18.6%)	**0.006**	0.859
Unemployed, n (%)	45 (10.7%)	22 (7.4%)	23 (18.6%)		**< 0.001**
Retired, n (%)	177 (42.3%)	128 (43.3%)	49 (39.8%)		0.502
Marital status	n = 416	n = 294	n = 122		p < 0.00625
Married, n (%)	264 (63.4%)	194 (65.9%)	70 (57.3%)		0.096
Divorced, n (%)	59 (14.1%)	37 (12.5%)	22 (18.0%)	0.276	0.147
Widowed, n (%)	15 (3.6%)	9 (3.0%)	6 (4.9%)		0.355
Single, n (%)	78 (18.0%)	54 (18.3%)	24 (19.6%)		0.756

Table 1. Description of the study sample—sociodemographic variables. n: number. y: years. SD: standard deviation. BIPQ: Brief Illness Perception Questionnaire. Significant p-values are marked bold. p-values for group analyses are based on an unpaired t-test for continuous variables, and a chi-square test for categorical variables. p-values for sugroup analyses are based on post-hoc Bonferroni correction.

	Total sample (n = 423)	BIPQ < 42 (n = 298)	BIPQ ≥ 42 (n = 125)	p-value ($p < 0.05$) group analysis	p-value subgroup analysis
	n = 388	n = 274	n = 114		
Number of ICD shocks in the past, mean (SD)	1.2 (5.3)	0.5 (1.3)	2.7 (9.5)	**0.015**	
	n = 408	n = 287	n = 121		
Past myocardial infarction, n (%)	154 (37.7%)	104 (36.2%)	50 (41.3%)	0.333	
ICD indication	n = 419	n = 295	n = 124	0.795	p < 0.0125
Primary, n (%)	246 (58.7%)	172 (58.3%)	74 (59.7%)		0.794
Secondary, n (%)	173 (41.3%)	123 (41.7%)	50 (40.3%)		0.794
Aetiology of cardiac disease (multiple answers possible)	n = 417	n = 294	n = 123		
Ischemic heart disease, n (%)	168 (40.3%)	118 (40.1%)	50 (40.7%)	0.979	
Congenital heart disease, n (%)	20 (4.8%)	12 (4.1%)	8 (6.5%)	0.301	
Cardiomyopathy, n (%)	128 (30.7%)	85 (28.9%)	43 (35.0%)	0.247	
Systemic disease with cardiac involvement, n (%)	40 (9.6%)	25 (8.5%)	15 (12.2%)	0.256	
Cardiac arrhythmia, n (%)	213 (51.1%)	153 (52.0%)	60 (48.8%)	0.489	
Valvular heart disease, n (%)	37 (8.9%)	30 (10.2%)	7 (5.7%)	0.133	
Heart failure category	n = 421	n = 296		**0.018**	p < 0.008
HFpEF (≥ 50%), n (%)	149 (35.4%)	116 (39.2%)	33 (26.4%)		0.012
HFmrEF (41–49%), n (%)	53 (12.6%)	39 (13.2%)	14 (11.2%)		0.576
HFrEF (≤ 40%), n (%)	219 (52.0%)	141 (47.6%)	78 (62.4%)		**0.005**
	n = 415	n = 293	n = 122		
Regular physical activity, n (%)	235 (56.6%)	177 (60.4%)	58 (47.5%)	**0.016**	
	n = 416	n = 294	n = 122		
Current smoking, n (%)	51 (12.2%)	37 (12.5%)	14 (11.4%)	0.753	
	n = 416	n = 294	n = 122		
Use of alcohol, n (%)	283 (68.0%)	207 (70.4%)	76 (62.2%)	0.106	
	n = 410	n = 288	n = 122		
Hospitalisation after ICD implantation, n (%)	199 (48.5%)	134 (46.5%)	65 (53.2%)	0.211	
	n = 409	n = 287	n = 122		
Cardiac rehabilitation after ICD implantation, n (%)	140 (34.2%)	87 (30.3%)	53 (43.4%)	**0.01**	
	n = 422	n = 297	n = 125		
ACE (ACE-Q), mean (SD)	1.1 (1.5)	0.9 (1.3)	1.5 (1.8)	**0.001**	
	n = 417	n = 294	n = 123		
ICD concerns (ICDC), mean (SD)	7.7 (7.8)	5.2 (5.8)	13.7 (8.6)	< **0.001**	

Table 2. Description of the study sample—clinical and lifestyle variables. Note: ICD: Implantable Cardioverter-Defibrillator. HFpEF: heart failure preserved ejection fraction. HFmrEF: heart failure moderately reduced ejection fraction. HFrEF: heart failure reduced ejection fraction. ACE: Adverse Childhood Experiences. ACE-Q: Adverse Childhood Experiences Questionnaire. ICDC : Implantable Cardioverter-Defibrillator Concerns Questionnaire. Significant p-values are marked bold. p-values for group analyses are based on an unpaired t-test for continuous variables, and a chi-square test for categorical variables. p-values for sugroup analyses are based on post-hoc Bonferroni correction.

Dimensional structure and internal consistency of the BIPQ

Bartlett's test of sphericity ($p < 0.001$) and the KMO-index (0.76) implied that our data met the assumptions for PCA. The scree plot indicated a clear break after the second factor, suggesting a two-factor structure. Both factors had eigenvalues > 1, and explained a variance of 54%: factor I (consequences) = 37%, and factor II (control) = 17% (Table 3). Factor I (Consequences) comprised item 1 (consequences), item 5 (identity), item 6 (concern), and item 8 (emotional response), while factor II (Control) included item 3 (personal control), item 4 (treatment control), and item 7 (understanding). Item 2 (timeline) did not belong to both factors.

The total scale and the consequences factor demonstrated acceptable to good internal consistency (α = 0.69, respectively, α = 0.88), but not the control factor (α = 0.29). Therefore, for statistical analyses we only used the total BIPQ score and the consequences subscale. Our approach equals a previous study[6].

Associations between ACE, IP, and further variables

A multivariable linear regression analysis highlighted significant associations of younger age and female sex with more threatening IP. A higher number of ICD shocks after ICD implantation and less physical activity were linked to a more threatening view with regard to the illness. Furthermore, more frequent ACE, greater ICD

	Total sample (n = 423)	
Variables	**Factor I**	**Factor II**
Item 1 consequences	**0.898**	0.018
Item 5 identity	**0.842**	-0.081
Item 6 concern	**0.859**	0.032
Item 8 emotional response	**0.807**	0.125
Item 3 personal control	0.040	**0.675**
Item 4 treatment control	0.024	**0.666**
Item 7 understanding	0.008	**0.657**
Item 2 timeline	0.092	-0.115
Eigenvalues	2.96	1.36
% of variance	37.02	17.05

Table 3. Dimensional structure of the BIPQ. Scale loadings assigned to a specific factor are marked bold.

	IP (BIPQ total score)		BIPQ consequences subscale (continuous score)	
Variables	**Estimate (95% CI)**	***p*-value**	**Estimate (95% CI)**	***p*-value**
Female sex	2.86 (0.26 to 5.47)	**0.031**	2.25 (0.32 to 4.18)	**0.022**
Age	-0.20 (-0.32 to -0.08)	**0.015**	-0.11 (-0.19 to -0.03)	**0.004**
Higher educational level	0.61 (-0.57 to 1.80)	0.313	0.52 (-0.35 to 1.41)	0.240
ICD shock number	0.21 (0.01–0.41)	**0.036**	0.25 (0.07–0.43)	**0.005**
Regular physical activity	-2.16 (-4.37 to -0.37)	**0.045**	-1.74 (-3.37 to -0.10)	**0.037**
ACE (ACE-Q total score)	0.56 (0.08–1.22)	**0.030**	0.60 (0.11–1.09)	**0.016**
Past myocardial infarction	0.65 (-1.78 to 3.09)	0.598	-0.69 (-2.50 to 1.11)	0.453
Marital status (married)	-0.39 (-2.60 to 1.81)	0.727	-0.46 (-2.10 to 1.17)	0.577
Use of alcohol	0.49 (-1.76 to 2.75)	0.668	0.37 (-1.30 to 2.04)	0.664
Smoking	-3.19 (-6.40 to 0.01)	0.051	-1.26 (-3.64 to 1.11)	0.296
Employment status (unemployed or retired)	0.69 (-0.57 to 1.97)	0.283	1.07 (0.08–2.06)	**0.034**
Hospitalisation after ICD implantation	0.31 (-1.79 to 2.42)	0.767	0.72 (-0.84 to 2.28)	0.363
Cardiac rehabilitation after ICD implantation	0.74 (-1.53 to 3.02)	0.520	0.66 (-1.02 to 2.35)	0.441
ICD concerns (ICDC total score)	0.75 (0.62–0.89)	< **0.001**	0.66 (0.56–0.76)	< **0.001**
ICD indication	-2.29 (-4.47 to -0.11)	**0.039**	-1.78 (-3.40 to -0.16)	**0.031**
Heart failure (reduced LVEF)	2.04 (0.75–3.33)	**0.002**	2.18 (1.22–3.13)	< **0.001**

Table 4. Multivariable linear regression for the IP total score and consequences subscale in ICD patients. IP: illness perceptions. LVEF: left ventricular ejection fraction. CI: confidence interval. Significant p-values are marked bold.

shock-related concerns, a primary ICD indication, and a reduced LVEF indicative of heart failure, predicted higher IP total scores (Table 4).

Another multivariable linear regression analysis explored associations of the consequences subscale of the BIPQ (Table 4). The variables that already demonstrated significant associations in the first regression model remained statistically significant in the second model. Additionally, higher scores of the consequences subscale were significantly associated with a higher likelihood of being unemployed or retired (employment status).

Besides, we included the aetiology of cardiac diseases as an additional covariate in another regression model (see Supplement 1), and removed the covariate past myocardial infarction due to its multicollinearity with the variable ischemic heart disease. As already demonstrated before, female sex, younger age, a higher number of ICD shocks in the past, regular physical activity, more frequent ACE, greater ICD shock-related concerns, and a reduced LVEF were associated with a more severe IP. Interestingly, a systemic disease with cardiac involvement had been also linked to more threatening IP (BIPQ total score: estimate 4.12, 95% confidence interval (CI) 0.04–8.19, $p = 0.047$; BIPQ consequences subscale: estimate 4.21, 95% CI 1.19–7.22, $p = 0.006$), while no other aetiology of cardiac disease indicated such an association.

Discussion

In this cross-sectional study, we explored the dimensional structure of the BIPQ, and analysed the IP profile of patients with an ICD and its associations with variables which have not previously been considered, such as ACE, ICD shocks, and physical activity.

To the best of our knowledge, only one other study examined the dimensional structure of the BIPQ in ICD patients until now[6]. In our study, factor loadings and the explained variance were slightly better than in the previous study[6], and, equally to that study[6], we identified in our dimensional analysis a two-factor structure, i.e., a consequences factor (Factor I: consequences, identity, emotional response, concern), and a control factor (Factor II: personal control, treatment control, understanding). The BIPQ total score and the consequences subscale demonstrated acceptable to good psychometric qualities, and thus were suited to measure IP in patients with an ICD. However, due to its low internal consistency, Factor II could not be established as a separate subscale to measure certain aspects of IP. This finding is supported by a previous study that conducted a PCA and identified treatment control and personal control to be separate components of the revised Illness Perceptions Questionnaire (IPQ-R) in end-stage renal disease patients[21]. In patients with CVD, including ICD patients, medical treatment is rather prescriptive compared to other diseases that require from patients to choose between treatment options. I.e., beliefs concerning control of the treatment may differ from beliefs about personal control over the illness in patients with an ICD.

Studies in other clinical populations, including cancer patients and patients with multimorbidity, confirmed the two-factor structure of the BIPQ with a consequences as well as a control dimension and timeline as separate dimension[22,23]. These past findings[6,22,23], together with the results of our study, imply that the theoretical concept which suggests a cognitive (causes, personal and treatment control, identity, timeline, consequences) and an emotional component of IP assessed with the BIPQ may not be the only valid theoretical framework[9,10,24,25]. Indeed, the two-factor structure of the BIPQ consisting of a consequences and a control dimension could rather reflect how patients think and feel about their illness (consequences), respectively, how patients might modify it in the future (control). Certainly, this alternative conception needs further validation in future studies.

One third of our participants reported at least moderate threatening IP, which is in line with another study of ICD patients and a suggested prevalence of 33%[6]. Our study also confirmed previous findings that female sex and younger age may be linked to more severe IP[6], and is supported by our observation that women tended to have greater ICD shock-related concerns than men. However, the prior study implied that rather psychological factors (such as poor health status, negative affectivity, or poor ICD acceptance) than clinical characteristics are associated with more threatening IP. To the contrary, our study demonstrated that a higher number of ICD shocks in the past may lead to higher IP. This finding is in line with other studies that indicated the significance of ICD shocks for the physical and psychological well-being in ICD patients[26,27]. In contrast to the precedent study[6], a primary ICD indication and a reduced LVEF were indicative of threatening IP. Heart failure, which can be divided into three categories based on the LVEF[19], has been also linked to worse IP scores in another recent study[8]. This observation is not surprising, since LVEF is known to be an important predictor of sudden cardiac death[28]. Although these results may have a certain clinical guiding significance, e.g. for patients with prophylactic ICD therapy, more studies are needed to confirm these observations. Furthermore, regular physical activity and not being unemployed or retired predicted a less threatening view of the illness. Interestingly, these variables have been shown to be significantly associated with mental and physical health outcomes in patients with an ICD in other studies[27,29]. Given that the previous literature suggested detrimental health outcomes for CVD and ICD patients with threatening IP[6–8], regular physical activity could be a simple and effective intervention to counteract those harmful effects. Psychological distress, e.g. in terms of ICD shock-related concerns, may be closely linked to IP, as has been implied in the past[6–8] and by the current study. Still, although psychological distress seems to be an integral aspect of IP and is suggested to be an outcome of coping and thus depends on how a person perceives an illness[7], our findings demonstrate the potential relevance of IP beyond psychological distress.

Of note, a higher frequency of ACE was associated with a more severe view of a patient's illness. This novel finding may be of great clinical significance and may explain a potential source of dysfunctional IP. To our best knowledge, there is no study which has investigated the relationship between ACE and IP in ICD patients so far. Yet, ACE are known to contribute to several physical and mental health problems in the general population[30,31], and a recent meta-analysis concluded that the elimination of ACE might lead to a significant reduction of depression, anxiety, cancer and other chronic diseases[32]. Besides, ACE have been associated with the development of CVD risk factors and CVD in later life[33], and with an increased risk of mortality[34]. Future studies should strive to understand the complex interplay between ACE, IP, as well as psychological and clinical characteristics to improve outcomes in patients with an ICD. There might be some interventions to help cope with ACE, and subsequently to reduce threatening IP in individuals. Trauma-informed care, e.g., might raise awareness and understanding of ACE and support affected adults at home or work[35]. Referrals to mental health care could be increased through ACE screening and thus aid to guide individual patient treatment[36]. Finally, although evidence on the effects of mindfulness with regard to CVD and ICD patients is scarce, a recent study demonstrated the beneficial value of dispositional mindfulness to reduce anxiety, depression, PTSD symptoms, and the quality of life in those patients[29]. Perhaps mindfulness-based interventions could lead to more benign views of a patient's illness. Additionally, some studies suggested modest changes with regard to specific interventions targeted at changing IP in patients after myocardial infarction[37,38]. Another recent study demonstrated that family caregivers' IP might affect coronary heart disease patients' cardiac rehabilitation intentions directly and indirectly through patients' IP[39]. Still, further studies are needed to assess the value of such interventions for patients with an ICD.

This study has several strengths, such as the large study sample and the investigation of novel predictors for threatening IP. However, there are also some limitations to this study. Since this study is cross-sectional, no causality can be inferred from our results. Longitudinal studies are required to assess potential causal effects of ACE and further variables on IP in ICD patients. The generalisability of our results is limited, since this study was conducted at a single-centre hospital. Additionally, the majority of our sample was male and our results may be thus not generalisable to women with an ICD, although these proportions are similar to other

studies which included ICD patients[6]. Our results may be also biased to a certain degree, e.g., with regard to the representativeness of the sample, the stability of statistical analysis, and variable relationships, because only 65% of our participants returned their questionnaires. Another limitation is the fact that we had no information on the rate of appropriate or inappropriate ICD shocks or the actual ICD shock interval. Theoretically, whether an ICD shock was delivered appropriately or inappropriately might impact patients' IP. Future research is warranted to elucidate this question. However, it is known that the rate of appropriate ICD shocks is relatively high and that inappropriate discharges have been associated with younger age and coronary artery bypass grafting in the past[40,41]. Lastly, we only used the BIPQ as short version of the IPQ-R with fewer items to measure IP, which might be another limitation of the study.

Conclusions

This study suggests that ACE, ICD shock-related concerns, low physical activity, and several cardiac variables, such as the frequency of ICD shocks in the past, a reduced LVEF, and primary ICD indication are associated with more threatening IP in patients with an ICD. Regular physical activities may improve the view of a patient's illness, but future studies are warranted to test this hypothesis. For example, prospective studies could aim to focus on formalised cardiac rehabilitation interventions to improve patients' IP. The exploration of the dimensional structure of the BIPQ revealed that not only the total score of all eight items, but also a total score of four items which loaded on the consequences dimension, might be suited to measure IP in ICD patients. However, this subscale should be treated with caution, since the clustering of items could vary among illnesses.

Data availability

The data presented in this study are available on request from the corresponding author.

Received: 30 June 2024; Accepted: 28 January 2025
Published online: 29 January 2025

References

1. Ghezzi, E. S. et al. Burden of mood symptoms and disorders in implantable cardioverter defibrillator patients: A systematic review and meta-analysis of 39954 patients. *Europace* **25**(6), euad130 (2023).
2. Dörner, M. et al. Fear of COVID-19 predicts depression, anxiety and post-traumatic stress disorders in patients with implantable cardioverter-defibrillators and is mediated by positive and negative affects—a cross-sectional study. *J. Clin. Med.* **12** (21), 6884 (2023).
3. Berg, S. K. et al. Do patients with ICD who report anxiety symptoms on hospital anxiety and depression scale suffer from anxiety? *J. Psychosom. Res.* **121**, 100–104 (2019).
4. Berg, S. K., Thygesen, L. C., Svendsen, J. H., Christensen, A. V. & Zwisler, A. D. Anxiety predicts mortality in ICD patients: Results from the cross-sectional national CopenHeartICD survey with register follow-up. *Pacing Clin. Electrophysiol.* **37**(12), 1641–1650 (2014).
5. Kapa, S. et al. Psychopathology in patients with ICDs over time: Results of a prospective study. *Pace* **33**, 198–208 (2010).
6. Timmermans, I. et al. Illness perceptions in patients with heart failure and an implantable cardioverter defibrillator: Dimensional structure, validity, and correlates of the brief illness perception questionnaire in Dutch, French and German patients. *J. Psychosom. Res.* **97**, 1–8 (2017).
7. Morgan, K., Villiers-Tuthill, A., Barker, M. & McGee, H. The contribution of illness perception to psychological distress in heart failure patients. *BMC Psychol.* **2**(1), 50 (2014).
8. Heart Failure and Patient-Reported. Outcomes in adults with congenital heart disease from 15 countries. *J. Am. Heart Assoc.* **11**, e024993 (2022).
9. Leventhal, H., Nerenz, D. R. & Steele, D. J. *Illness Representations and Coping with Health Threats. Handbook of Psychology and Health* 219–252 (Hillsdale, 1984).
10. Lau, R. R., Bernard, T. M. & Hartman, K. A. Further explorations of common-sense representations of common illnesses. *Health Psychol.* **8**(2), 195–219 (1989).
11. Godoy, L. C. et al. Association of adverse childhood experiences with cardiovascular disease later in life. *JAMA Cardiol.* 228–235 (2021).
12. Felitti, V. J. et al. Relationship of childhood abuse and household dysfunction to many of the leading causes of death in adults. The adverse childhood experiences (ACE) study. *Am. J. Prev. Med.* **14**(4), 245–258 (1998).
13. Cronholm, P. F. et al. Adverse childhood experiences: expanding the concept of adversity. *Am. J. Prev. Med.* **49**(3), 354–361 (2015).
14. Merrick, M. T., Ford, D. C., Ports, K. A. & Guinn, A. S. Prevalence of adverse childhood experiences from the 2011–2014 behavioral risk factor surveillance system in 23 states. *JAMA Pediatr.* **172**(11), 1038–1044 (2018).
15. Anda, R. F. et al. The enduring effects of abuse and related adverse experiences in childhood. A convergence of evidence from neurobiology and epidemiology. *Eur. Arch. Psychiatry Clin. Neurosci.* **256** (3), 174–186 (2006).
16. Suglia, S. F. et al. Childhood and adolescent adversity and cardiometabolic outcomes: A scientific statement from the American Heart Association. *Circulation* **137**(5), e15–e28 (2018).
17. Kuiper, H. et al. Reliability and validity of the brief illness perception questionnaire (B-IPQ) in individuals with a recently acquired spinal cord injury. *Clin. Rehabil.* **36**(4), 550–557 (2021).
18. Thylén, I. et al. Concerns about implantable cardioverter-defibrillator shocks mediate the relationship between actual shocks and psychological distress. *Europace* **18**(6), 828–835 (2016).
19. McDonagh, T. A. et al. 2021 ESC guidelines for the diagnosis and treatment of acute and chronic heart failure. *Eur. Heart J.* **42**(36), 3599–3726 (2021).
20. Kutner, M. H. *Applied Linear Statistical Models* 410 (McGraw-Hill Irwin, 2005).
21. Chilcot, J., Norton, S., Wellsted, D. & Farrington, K. The factor structure of the revised illness perception questionnaire (IPQ-R) in end-stage renal disease patients. *Psychol. Health Med.* **17**(5), 578–588 (2012).
22. Karatas, T., Ozen, S. & Kutluturkan, S. Factor structure and psychometric properties of the brief illness perception questionnaire in Turkish cancer patients. *Asia Pac. J. Oncol. Nurs.* **4**(1), 77–83 (2017).
23. Schuz, B., Wolff, J. K., Warner, L. M., Ziegelmann, J. P. & Wurm, S. Multiple illness perceptions in older adults: Effect on physical functioning and medication adherence. *Psychol. Health Med.* **29**(4), 442–457 (2014).
24. Broadbent, E., Petrie, K. J., Main, J. & Weinmann, J. The biref illness perception questionnaire. *J. Psychosom. Res.* **60**(6), 631–637 (2006).
25. Basu, S. & Poole, J. The brief illness perception questionnaire. *Occup. Med.* **66**(5), 419–420 (2016).

26. Ghezzi, E. S. et al. Burden of mood symptoms and disorders in implantable cardioverter defibrillator patients: A systematic review and meta-analysis of 39,954 patients. *Europace* **25**, euad130 (2023).
27. Mastenbroek, M. H. et al. Trajectories of patient-reported health status in patients with an implantable cardioverter defibrillator. *Am. J. Cardiol.* **115**, 771–777 (2015).
28. Santini, M., Lavalle, C. & Ricci, R. P. Primary and secondary prevention of sudden cardiac death: Who should get an ICD? *Heart* **93**(11), 1478–1483 (2007).
29. Dörner, M. et al. Mindfulness is Associated with Lower Depression, anxiety, and post-traumatic stress disorder symptoms and higher quality of life in patients with an Implantable Cardioverter-Defibrillator—A cross-sectional study. *Healthcare* **12**(11), 1118 (2024).
30. Suglia, S. F. et al. Social determinants of cardiovascular health: Early life adversity as a contributor to disparities in cardiovascular diseases. *J. Pediatr.* **219**, 267–273 (2020).
31. Havranek, E. P. et al. Council on Epidemiology and Prevention, Council on Cardiovascular and Stroke nursing, Council on Lifestyle and Cardiometabolic Health, and Stroke Council. Social determinants of risk and outcomes for cardiovascular disease: A scientific statement from the American Heart Association. *Circulation* **132**(9), 873–898 (2015).
32. Bellis, M. A. et al. Life course health consequences and associated annual costs of adverse childhood experiences across Europe and North America: A systematic review and meta-analysis. *Lancet Public Health* **4**(10), e517–e528 (2019).
33. Dong, M. et al. Insights into causal pathways for ischemic heart disease: Adverse childhood experiences study. *Circulation* **110**(13), 1761–1766 (2004).
34. Brown, D. W. et al. Adverse childhood experiences and the risk of premature mortality. *Am. J. Prev. Med.* **37**(5), 389–396 (2009).
35. Raja, S., Hasnain, M., Hoersch, M., Gove-Yin, S. & Rajagopalan, C. Trauma informed care in medicine: Current knowledge and future research directions. *Fam. Community Health* **38**(3), 216–226 (2015).
36. Anda, R. F., Porter, L. E. & Brown, D. W. Inside the adverse childhood experience score: Strengths, limitations, and misapplications. *Am. J. Prev. Med.* **59**(2), 293–295 (2020).
37. Broadbent, E., Ellis, C. J., Thomas, J., Gamble, G. & Petrie, K. J. Further development of an illness perception intervention for myocardial infarction patients: a randomized controlled trial. *J. Psychosom. Res.* **67**(1), 17–23 (2009).
38. Petrie, K. J., Cameron, L. D., Ellis, C. J., Buick, J. & Weinman, J. Changing illness perceptions after myocardial infarction: An early intervention randomized controlled trial. *Psychosom. Med.* 580–586 (2002).
39. Xie, Y. et al. Relationship between older coronary heart disease patients' phase II cardiac rehabilitation intentions, illness perceptions, and family caregivers' illness perceptions. *Heart Lung* **70**, 183–190 (2024).
40. Catanzaro, J. N. et al. Clinical predictors of appropriate implantable-cardioverter defibrillator discharge. *Pacing Clin. Electrophysiol.* **30**(Suupl 1), S120–S124 (2007).
41. Pezzato, A. et al. Implantable-cardioverter-defibrillator after ST-elevation myocardial infarction: When and how frequently is it implanted and what is the rate of appropriate interventions? Insight from Trieste registry. *J. Cardiovasc. Med.* **24** (12), 871–879 (2023).

Author contributions

Conceptualisation and design, M.D., R.v.K., M.P.; Literature research, M.D.; Data analysis and interpretation, M.D.; Critical revisions, M.D., R.v.K., A.P.P., R.A., N.K., L.N., V.A., L.G., S.Z., A.M., C.Z.-H., M.P.; Writing—creating Tables, M.D.; Writing—Original Draft Preparation, M.D; Writing—Review and Editing, M.D., R.v.K., A.P.P., R.A., N.K., L.N., V.A., L.G., S.Z., A.M., C.Z.-H., M.P. All authors have read and agreed to the published version of the manuscript.

Funding

This research received no external funding.

Declarations

Competing interests

The authors declare no competing interests.

Institutional review board statement

The study was conducted according to the guidelines of the Declaration of Helsinki, and approved by the Ethics Committee of the State of Zurich, Switzerland (BASEC no. 2019 – 01948; 12/2019).

Informed consent

Informed Consent was obtained from all subjects involved in the study.

Additional information

Supplementary Information The online version contains supplementary material available at https://doi.org/10.1038/s41598-025-88470-x.

Correspondence and requests for materials should be addressed to M.D.