Benefits of support groups for patients living with implantable cardioverter defibrillators: a mixed-methods systematic review and meta-analysis

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ABSTRACT

Background Patients with implantable cardioverter defibrillators (ICDs) experience anxiety, depression and reduced quality of life (QoL).

Objectives This mixed-methods systematic review evaluates whether ICD support groups have a beneficial effect on mental well-being.

Methods Literature searches were carried out in MEDLINE, Embase, CINAHL, PsycINFO and Web of Science. Eligible studies investigated patient-led support groups for ICD patients aged 18 years or older, using any quantitative or qualitative design. The Mixed-Methods Assessment Tool was used to assess quality. Meta-analysis of measures of mental well-being was conducted. Thematic synthesis was used to generate analytic themes from the qualitative data. The data were integrated and presented using the Pillar Integration Process.

Results Ten studies were included in this review. All studies bar one were non-randomised or had a qualitative design and patients had self-selected to attend a support group. Five contributed to the quantitative data synthesis and seven to the qualitative synthesis. Meta-analysis of anxiety and QoL measures showed no significant impact of support groups on mental well-being, but qualitative data showed that patients perceived benefit from attendance through sharing experiences and acceptance of life with an ICD.

Discussion ICD support group attendance improved the patients’ perceived well-being. Attendees value the opportunity to share their experiences which helps to accept their new life with an ICD. Future research should consider outcomes such as patient acceptance and the role of healthcare professionals at support groups.

WHAT IS ALREADY KNOWN ON THIS TOPIC

⇒ Patients with implantable cardioverter defibrillators (ICDs) experience anxiety, depression and reduced quality of life (QoL). Patient support groups are recommended in national guidelines for follow-up of patients with ICDs.

WHAT THIS STUDY ADDS

⇒ Patients perceive an improvement in overall mental well-being from attending ICD support groups, although this is not supported by quantitative measures of anxiety and QoL. Acceptance may be a more sensitive measure of the effect of support groups.

HOW THIS STUDY MIGHT AFFECT RESEARCH, PRACTICE OR POLICY

⇒ Support groups may be helpful for patients struggling to accept their ICD, and patient discussion should be encouraged to allow sharing of experiences. Further research is needed to determine the optimal format of support groups.

INTRODUCTION

Implantable cardioverter defibrillators (ICDs) were introduced to prevent sudden cardiac death (SCD), most frequently caused by coronary artery disease (80% of cases). ICDs were originally implanted as a secondary prevention strategy, with guidelines being expanded in the early 2000s to include patients at risk of SCD (primary prevention). Implant rates in England quadrupled between 2002 and 2020. Patients with ICDs experience anxiety and depression. This may be present in patients with or without ICD-delivered shocks, but is increased by higher incidence of shocks. The delivery of a shock to restore sinus rhythm has been shown to cause a transient reduction in quality of life (QoL). Anxiety and reduced QoL is associated with increased readmissions and 1-year mortality for ICD patients. It has also been suggested that there is a correlation between anxiety and the occurrence of arrhythmia.

A range of psychological and educational interventions to improve psychological outcomes for patients with ICDs have been investigated. The results of these studies are promising but methodological limitations restrict the extent to which they can be...
generalised and applied to clinical practice. At present, UK guidance for ICD follow-up and high-profile cardiac charities encourage participation in patient support groups. Patient support groups are defined as groups with aims determined by the participants (rather than the providers) and without structured curriculum or end date. Support groups also provide an option for supportive care using limited healthcare resources.

There are many support groups for patients with chronic conditions such as cancer and heart failure. These groups provide benefits for the patients, such as the opportunity to meet and talk with people with the same condition or experiences, and for information provision and exchange. Although ICD recipients share experiences of patients with other long-term conditions, their risk of recurrent shocks is something unique to these patients and it remains to be seen whether support groups also have a beneficial impact on well-being in ICD patients.

The objectives of this mixed-methods systematic review are to: (1) evaluate the effectiveness of patient support groups on mental well-being in patients living with ICDs using a meta-analysis and (2) define the perceived benefits and challenges of attending a support group, using a qualitative synthesis.

METHODS

Design and registration
This mixed-methods systematic review was prospectively registered (PROSPERO: CRD42021262058) and reported in line with the Preferred Reporting Items for Systematic Reviews and Meta-Analyses statement.

Inclusion criteria

Participants
The patients in the studies had to be 18 years or older and have had an ICD implanted, including single or dual, or biventricular devices.

Comparators
To be defined as a patient support group, it must have (1) aims determined by the participants rather than the providers and (2) no structured curriculum with a defined beginning or end. This definition of a patient support group is that used in a published scoping review. Involvement of healthcare professionals (HCPs) to provide education was permitted provided the objectives of the group were patient-led. Forms of HCP-led psycho-social support, including cognitive behavioural therapy, exercise programmes and psycho-educational interventions with a clear curriculum and set duration were excluded. The comparison was standard care of the ICD without attendance of a support group.

Outcomes
For quantitative studies the main outcomes were selected a priori and are ‘changes in measures of mental well-being’. The definition of ‘mental well-being’ is complex but it is widely understood to mean more than simply absence of mental illness and includes the ability to cope with stressors and work productively. We chose to include measures of QoL, anxiety and depression as outcomes which are aspects of mental well-being. Instruments to assess these outcomes included general (ie, State-Trait Anxiety Index) and ICD specific (ie, Florida Shock Anxiety Scale (FSAS)) measures. QoL measures included but were not limited to the Short-Form 36 (SF-36) and the Quality of Life Index (QLI). ‘Social support’ was added later in the analysis as it was frequently measured. For qualitative studies, the outcomes were anxiety, depression, QoL, benefits and challenges of attending support groups.

Types of evidence
A range of study designs, including quantitative, qualitative and mixed-methods designs, were included to allow for review of the totality of existing evidence.

Search strategy and screening
Five databases were searched in July 2021. The initial search strategy was developed for MEDLINE (see table 1) and adapted for Embase, CINAHL, PsychINFO and Web of Science.

A search filter was used to include all papers published from January 1980 until July 2021. A search of grey literature included hand searches of conference abstracts between 2019 and 2021 (British Cardiovascular Society and Heart Rhythm Congress). Reference lists of included articles were searched for potential eligible papers. Non-English language articles were excluded. KHS screened all records by title before two authors (KHS/PAC) screened potentially eligible abstracts and full-texts. Where there was disagreement, a third reviewer’s (MA) opinion was sought.

The database search was repeated in July 2022 to check for new publications. No eligible papers were identified.

Quality assessment
The Mixed-Methods Assessment Tool (MMAT) was used by two independent reviewers (KHS and PAC) to assess quality and risk of bias. The MMAT was designed...
to appraise the methodological quality of five categories of studies (qualitative research, randomised controlled trials, non-randomised studies, quantitative descriptive studies and mixed-methods studies), and was therefore chosen as the most suitable tool for the current study due to the methodological variety of studies included.

Data extraction and analysis

KHS extracted the design, population, sex, age, comparator, outcome measures, instruments used and key findings from the included articles. Quantitative results were grouped by outcomes indicative of ‘better mental well-being’ including measures of anxiety and QoL. A meta-analysis using pooled outcome measurements was conducted using Review Manager V.5.4.36 This approach has been used in other published studies.29 30 To allow comparison of data from different instruments, mental well-being data of each parameter was normalised to the average control value for that parameter. Where multiple measures were used in a study, a single parameter was chosen for the analysis with preference to measures of anxiety over generalised QoL. Adjusted data were pooled to calculate weighted standardised mean difference and 95% CIs. Overall effect was calculated using a Z-test.

Qualitative results were uploaded verbatim to NVivo V.11 and thematic synthesis methods31 used to generate themes. KHS deductively coded for anxiety and depression, and quality of life, and developed inductive codes around perceived benefits and challenges of attending support groups. The quantitative and qualitative data were then integrated and are presented in a joint display using the Pillar Integration Process (PIP).32 A mixed-methods systematic review using the PIP was chosen as the PIP permits grouping of outcomes based on conceptual ideas, rather than the quantity of each item or the research methods used.32

Patient and public involvement

The results of this study were disseminated to members of a Patient and Public Involvement group.

RESULTS

Study characteristics

From 456 records identified, 10 papers were eligible for inclusion (figure 1). Most records were excluded because they did not include a support group. Two studies were excluded because the support group intervention was restricted to a set period and therefore had a set curriculum.10 33 Tables 2 and 3 include the summary characteristics and results for the 10 studies: one randomised controlled trial (RCT),34 two observational studies,35 36 two mixed-methods studies,37 38 four qualitative studies39–42 and one service evaluation.43

One study was based in Australia34 and one in Turkey.34 The remainder were from the USA. In all studies the support group attendees were predominantly male (range 53%–91%). The support groups varied considerably in terms of attendee age, format and frequency (table 4).

Four papers34–37 contributed to the quantitative synthesis and were used in the meta-analysis for mental well-being (figure 2). Three of the four reported the mean value of age of attendees but one37 reported only a range. We contacted the authors for this information, but the raw data was no longer available.

Seven papers37–43 contributed to the qualitative synthesis. The data from the two mixed-methods studies were extracted and analysed as separate quantitative and qualitative data because quality assessment indicated the rationale for, and integration of, mixed methodology was poor as indicated by the MMAT (table 5). Table 5 shows how each study was appraised using the relevant questions to the category of study. Higher quality is indicated by higher proportion of positive responses to the questions. Overall, the more recent qualitative studies were of better quality than those published prior to 2000. Quantitative studies included in our meta-analysis had satisfactory quality, answering ‘yes’ to six out of seven questions.

Integrated synthesis of quantitative and qualitative data are shown in table 6, where priority was given to studies with better quality ratings as determined by the MMAT (table 5).

Quantitative analysis

Anxiety and depression

Three studies34 36 37 measured anxiety using validated instruments: State Trait Anxiety Inventory, Visual Analogue Scale-Anxiety (VAS-A) and FSAS. No quantitative data on depression was found. Only two studies34 37 measured the effect of support groups on anxiety over time; neither demonstrated a significant difference between support group attendees and non-attendees.

Anxiety measured by the FSAS decreases over time in all groups.34 There was an increase in anxiety over time measured by the VAS-A, but no change in state anxiety.37 Support group attendees tended to be more anxious than non-attendees in observational studies.36 37

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**Table 2** Characteristics of randomised controlled trials

| Study | Design | Population | Sex | Age | Comparator | Outcome measures |
|-------|--------|------------|-----|-----|------------|------------------|
| Study A | RCT     | Australia  | Male | 18-65 | Support group | State Trait Anxiety Inventory |
| Study B | RCT     | USA        | Male | 18-65 | Support group | Visual Analogue Scale-Anxiety (VAS-A) |

**Table 3** Characteristics of observational studies

| Study | Design | Population | Sex | Age | Comparator | Outcome measures |
|-------|--------|------------|-----|-----|------------|------------------|
| Study C | Observational | USA | Male | 18-65 | Support group | State Trait Anxiety Inventory |
| Study D | Observational | USA | Female | 18-65 | Support group | Visual Analogue Scale-Anxiety (VAS-A) |

**Table 4** Characteristics of mixed-methods studies

| Study | Design | Population | Sex | Age | Comparator | Outcome measures |
|-------|--------|------------|-----|-----|------------|------------------|
| Study E | Mixed-methods | USA | Male | 18-65 | Support group | State Trait Anxiety Inventory |
| Study F | Mixed-methods | USA | Female | 18-65 | Support group | Visual Analogue Scale-Anxiety (VAS-A) |

**Table 5** Characteristics of qualitative studies

| Study | Design | Population | Sex | Age | Comparator | Outcome measures |
|-------|--------|------------|-----|-----|------------|------------------|
| Study G | Qualitative | USA | Male | 18-65 | Support group | State Trait Anxiety Inventory |
| Study H | Qualitative | USA | Female | 18-65 | Support group | Visual Analogue Scale-Anxiety (VAS-A) |

**Table 6** Characteristics of service evaluation study

| Study | Design | Population | Sex | Age | Comparator | Outcome measures |
|-------|--------|------------|-----|-----|------------|------------------|
| Study I | Service evaluation | USA | Male | 18-65 | Support group | State Trait Anxiety Inventory |

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Sanders KH, et al. Open Heart 2022;9:e002021. doi:10.1136/openhrt-2022-002021

**Figure 1** Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) 2020 flow diagram.
### Table 2: Summary of characteristics and results from included quantitative studies

| Author and country | Research aims | Research design | Sample characteristics | Outcome measures | Instruments | Key results | Key findings |
|--------------------|---------------|----------------|------------------------|------------------|-------------|-------------|-------------|
| Yardımcı and Mert<sup>11</sup> Turkey | To compare shock-related anxiety and quality of life in those who access a web-based intervention programme and those receiving usual care | Quantitative randomised, single blind controlled trial | Randomised sample (76 participants) with ICDs>18 years, being able to use computer and internet, able to understand and speak Turkish. Neurological and psychiatric disorders excluded. Intervention: 82.1% male, mean age 46.2 years. Control: 75.7% male, mean age 50.9 years | Collected at 3 time points (baseline, 3 months, 6 months): ICD shock-related anxiety. QoL | Florida Shock Anxiety Scale (Turkish version) and Short Form Health Survey (SF-36, Turkish version) | Mean FSAS at baseline: intervention 14.36, control 17.37 (p=0.207). Mean FSAS after 6 months: intervention 13.30, control 16.78 (p=0.083) | Shock-related anxiety over time; no significant difference between intervention and control groups. No significant difference was found in the mean mental or physical summary component score of the SF-36, but significant differences were seen in subdimensions of social functioning, role-physical, mental health, vitality and bodily pain |
| Myers and James<sup>9</sup> USA | To compare demographics, ICD-related characteristics, anxiety and social support in those who attend a patient support group and those who do not. To investigate the relationships between reason for ICD implant, anxiety and social support | Quantitative non-randomised: observational | Convenience sample (150 participants) 50–80 years, first ICD implant, no battery changes, intact cognitive status, able to read, write and understand English. Attendees: (73 participants) 75.3% male, mean age 67.7 years. Non-attendees: (77 participants) 84.4% male, mean age 68.4 years | Social support, anxiety. Collected at single time point | Sarason's 6-item Social Support Questionnaire, State-Trait Anxiety Inventory | Mean state anxiety: attendees 35.21, non-attendees 33.1 (p=0.23). Mean trait anxiety: attendees 37.01, non-attendees 33.36 (p<0.05). Mean satisfaction with social support: attendees 32.03, non-attendees 33.77 (p=0.03) | Groups differed on level of education and household income, and reason for implant. Those attending support group had higher satisfaction with the social support and trait anxiety than non-attendees. Irregular tachycardia associated with higher trait anxiety. Satisfaction with social support has a negative relationship with anxiety. Satisfaction with support has a positive relationship with social network |
| Dickerson et al<sup>9</sup> USA | To compare demographics, ICD-related characteristics, social support and quality of life in those who attend a patient support group and those who do not. To investigate the relationship between demographic and clinical factors and QoL | Quantitative non-randomised: observational | Convenience sample (328 surveys mailed, 112 returned: 34% response) of all patients who received ICD at a single centre over 10-year period. Attendees (27 participants) 79% male, mean age 61.8 years. Non-attendees (85 participants) 79% male, mean age 63.2 years | QoL, social support, demographics. Collected at single time point | Ferrans and Powers' Quality of Life Index (QLICV). No instrument used for social support | QLI: attendees mean 23.7, non-attendees 23.0 (p=0.77) | No significant different in QLI scores between attendees and non-attendees of support group. Support group attendance was associated with higher level of education, higher ejection fraction, higher number of supports and value of supports. Age and frequency of shocks were not related to QoL. Comorbidity is related to QoL |
| Molchany and Peterson<sup>11</sup> USA | To compare anxiety and social functioning in those who attend a patient support group and those who do not | Mixed-methods (qualitative-quantitative non-randomised) | Convenience sample (36 participants) of those able to attend support group and willing to attend monthly group meeting for 9 months. ICD recipients (11 participants) 91% male, age range 56–75 years. Significant others (10 participants) 10% male, age range 51–90 years. Non-attendees (5 participants) 80% male, age range 51–75 years | Collected at 2 time points (baseline, 9 months attendance only): Anxiety, social functioning and adaptation, demographics | Anxiety Visual Analogue Scale (VAS), State Anxiety Index, Medical Outcomes Study (MOS) short-form general health survey | Mean state anxiety at baseline: attendees 36.4, non-attendees 33.8. Mean state anxiety after 9 months: attendees 34.8 (p=0.399). Mean VAS at baseline: attendees 20.35, non-attendees 22.5. Mean VAS after 9 months: attendees 34.22. MOS data incomplete | Anxiety scores did not vary significantly between attendees and non-attendees (both groups were in the normal range), nor did they decrease between time points. No significant difference in social functioning between attendees and non-attendees at baseline. Time point 2 data incomplete and not reported |
Attendees had significantly higher trait anxiety than non-attendees, although this was not significant for state anxiety.

Quality of life
QoL was measured in two quantitative studies using the SF-36 and QLI. Neither study recorded a significant difference in overall summary scores between support group attendees and non-attendees. There was significant improvement in specific subscales of the SF-36 (social functioning, role-physical, mental health, vitality, and bodily pain) in support group attendees. Age and frequency of shocks were not related to QLI, however, greater comorbidity was found to correlate with reduced QoL.

Social support
Social support was not identified as an outcome a priori for this review but was measured in three quantitative studies. Support group attendance was associated with lower satisfaction with social support. Patients also felt that positive role modelling contributed to the benefit of support groups.

Qualitative analysis
Patients reported that fear of death and of ICD shocks were the source of their anxiety. Knowing a stick of dynamite may go off at anytime and you have little warning, is a head game you are invited to participate in each morning when you wake up. (39, p161)

Attending a support group helped them to control their fear and anxiety through knowledge acquisition and decision-making skills, including making contingency plans. Patients also felt that positive role modelling was an important aspect.

| Author country | Research aims | Research design | Sample characteristics | Outcome measures | Instruments | Key results | Key findings |
|----------------|---------------|-----------------|------------------------|-----------------|-------------|-------------|-------------|
| Serber et al. | To examine the acceptability of online and interactive nurse-facilitated support groups for the in-person participants | Mixed-methods qualitative descriptive (quantitative descriptive) | Convenience sample (46 participants) of support group attendees. No exclusions. ICD recipients (29 participants) 62.1% male. Caregivers (17 participants) 11.8% male. Exact age not collected. 81% of participants were >60 years | Acceptability of format to in-person attendees. One time survey | Self-report questionnaire to measure satisfaction with the group format: developed for this study, 8 5-point Likert-style questions | Overall satisfaction with the group format: 63% very satisfied, 28.3% somewhat satisfied, 2.2% neither satisfied or dissatisfied, 6.5% very dissatisfied | High acceptability of the webcast and group format |

FSAS, Florida Shock Anxiety Scale; ICD, implantable cardioverter defibrillator; MOS, Medical Outcomes Study; QLI:CV, quality of life index: cardiovascular; QoL, quality of life; VAS, Visual Analogue Scale.
| Author, Country | Research Aims | Research Design | Population | Outcome Measures | Instruments | Key Findings |
|----------------|--------------|-----------------|-------------|------------------|------------|--------------|
| Molchany and Peterson, USA | To describe the incidence of group members sharing feelings and experiences and offering social support to other group members | Mixed-methods (qualitative + quantitative non-randomised) | Convenience sample (26 participants). ICD patients and their significant others, able to attend support group and willing to attend monthly group meeting for 9 months. ICD recipients (11 participants) 91% male, age range 56–75 years. Significant others (10 participants) 10% male, age range 51–90 years. Non-attendees (5 participants) due to illness/travel restrictions as comparison group: 80% male, age range 51–75 years | Incidents of sharing and emotional support | Notes or tape recordings of leader’s accounts of the meeting | Qualitative data highlighted need for gender specific education and support |
| Serber et al, USA | To examine the acceptability of online and interactive nurse-facilitated support groups for the in-person participants | Mixed-methods (qualitative descriptive + quantitative descriptive) | Convenience sample (46 participants) of support group attendees. No exclusions. ICD recipients (29 participants) 62.1% male. Caregivers (17 participants) 11.8% male. Exact age not collected. 81% of participants were >60 years | Acceptability of format to in-person attendees. One time survey | Self-report questionnaire to measure satisfaction developed for this study with 2 open ended questions | Themes: (1) Gaining information and interaction, (2) benefiting others and accessibility, (3) gaining support and education |
| Williams et al, Australia | To describe the experiences, concerns and needs of ICD recipients and family caregivers. | Qualitative exploratory descriptive | Purposive sampling (22 participants) of ICD recipients from a single centre, >18 years, able to speak, read and understand English or be able to respond through an interpreter. ICD recipient (11 participants) 73% male. Caregivers (11 participants) 18% male. Exact age not collected. 18% of participants were >60 years. In each group there were 6 attendees and 5 non-attendees | Experiences of living with an ICD. Experiences of attending a support group | Semi-structured interviews face-to-face or telephone | Four themes focussing on reasons why participants attend or do not attend support groups. Themes: (1) providing information, (2) connecting with others, (3) helping others, (4) attendance |
| Dickerson et al, USA | To explore the lived experience of help seeking in a support group for recipients of ICDs and their support persons | Qualitative Heideggarian hermeneutic phenomenology | Convenience sample (24 participants) of support group attendees. No exclusions. ICD recipients (15 participants) 60% male, mean age 65 years. Support persons (9 participants) 44% male, mean age 67 years | Lived experience of attending an ICD support group | Focus groups and semi-structured interviews | Themes and constitutive pattern: (1) hearing and telling stories, (2) triggers that encourage seeking help from group, (3) meaningful information, (4) group camaraderie as therapeutic friendship, (5) importance of a facilitator (6) support persons’ similar view. Constitutive pattern: coping with the possibility of death |

*Continued*
| Author and year | USA | Research aims | Research design | Population | Outcome measures | Instruments | Key findings |
|-----------------|-----|---------------|-----------------|------------|-----------------|------------|-------------|
| Dickerson et al | USA | To explore the common themes and shared meanings of internet discussions on an informal public electronic bulletin board for persons with ICDs | Qualitative Heideggerian hermeneutic phenomenology | 75 users of an online bulletin board for persons with ICDs (55 ICD recipients, 5 family caregivers, 15 others including doctors, nurses and friends). 30 users gender identified, 53% male. 25 users age identified, mean age 42.8 years | Frequency of postings, content of postings | Observation and collection of fifteen months of postings on the public bulletin board | Themes and constitutive pattern: (1) seeking and giving meaningful information, (2) sharing personal perspectives, (3) storytelling as common grounding, (4) supportive teaching. Constitutive pattern: therapeutic connection |
| Dickerson | USA | To explore the practical knowledge gained from internet use by implantable cardioverter defibrillator (ICD) recipients | Qualitative Heideggerian hermeneutic phenomenology | Convenience sample (13 participants) of ICD recipients who were members of the online community. 70% male, mean age 41.2 years | Experience of seeking online support | Online virtual focus group and follow-up email interviews | Themes and constitutive pattern: (1) getting past fear with knowledge and support, (2) gaining context through a window into the future, (3) internet as a mountain of information: a goldmine of ICD knowledge, (4) internet as social interaction, (5) becoming informed consumers. Constitutive pattern: gaining a context for a healthy life with an ICD |
| Teplitz et al | USA | To describe the development of a support group for ICD recipients and their families | Service evaluation | 34 ICD recipients returned questionnaire prior to group set-up. Informal feedback collected from patients and families at support group meetings. Gender data not recorded. Age range of attendees 21–77 years | Experiences of developing and facilitating a support group | Brief questionnaire—no detail of content. Observation of group and recording of informal feedback by facilitators | Questionnaire indicated high interest in support group attendance (88% indicated they would attend). Describes common themes for patient concerns (fear of shock, travel, driving, adapting to new family role), facilitator strategies to maintain group cohesion, perceived benefits by patients (sharing experiences, feeling connected) |

ICD, implantable cardioverter defibrillator.
and sharing of experiences within the group helped to manage depression.40,41

I need to turn to a source where I find comments, questions, fears, joys, whatever, also shared by me, that indicate I’m normal to this select group. (41, p253)

Patients experienced dependency and low self-esteem post implant, affecting relationships43 and preventing acceptance of their ICD.37 Encouragement from other group members to resume normal life activities helped patients manage their depression.37,43

Quality of life

Patients found that the support group helped them find ways to live with their ICD and deal with their limitations.39,40 Attending the group improved their knowledge and understanding of the device,39–42 which in turn led to a return to ‘normal’ life and activities.37,43

Social support

Patient support groups provide a social setting which allow new friendships to form.40,42 Patients reported difficulties with existing support as family and friends do not understand their experiences.41,43 Social bonding in the support group provides a setting for humour regarding ICDs,39 that was found to facilitate healing and coping.40

There were comical things that happened, one guy was holding his dog when it [ICD] went off and for a

Table 4 Assessment of heterogeneity of support group attendees, format and frequency

| Author            | Country | Support group attendee age (years) | Support group attendee gender (% male) | Support group location | Support group format                                                                 | Support group meeting frequency |
|-------------------|---------|----------------------------------|----------------------------------------|------------------------|---------------------------------------------------------------------------------------|---------------------------------|
| Yardımcı and Mert  | Turkey  | Mean 46.2                         | 82.1                                   | Online                 | Living with an ICD website. Education modules available. Patients able to initiate and respond to web-based discussions | Continuously available          |
| Myers and James   | USA     | Mean 67.7                         | 75.3                                   | In person              | 10 different in-person support groups utilised, all led by facilitator with ICD expertise, lasted at least 2 hours, with educational and support component | Range 4–10 per year             |
| Dickerson et al   | USA     | Mean 61.8                         | 79                                     | In person              | In-person group meeting facilitated by a cardiac nurse specialist, consisting of open discussion and sharing, followed by a question-and-answer session | 12 per year                    |
| Molchany and Peterson | USA | Range 56–76                       | 91                                     | In person              | In-person group meeting led by a psychiatric clinical nurse and a cardiac clinical nurse specialist | 12 per year                    |
| Serber et al      | USA     | 81% > 60                          | 62.1                                   | In person and online   | Group meeting held in-person and simultaneously cast on the internet with remote attendees. Guided by nurse facilitator and structured to provide education and support | 12 per year                    |
| Williams et al    | Australia | 18% > 60                          | 73                                     | In person              | In-person group meeting consisting of education, question time and opportunities for participants to share | 2 per year                     |
| Dickerson et al   | USA     | Mean age 65                        | 60                                     | In person              | Group meeting facilitated by cardiac nurse specialist, consisting of open discussion and sharing, followed by question-and-answer session | 12 per year                    |
| Dickerson et al   | USA     | Mean 42.8 (incomplete data)       | 53 (incomplete data)                   | Online                 | On-line, informal, public electronic bulletin board                                   | Continuously available; live chat meeting 2 per week |
| Dickerson        | USA     | Mean 41.2                         | 70                                     | Online                 | Online community website providing newsletters, bulletin board, live chat, FAQs, ICD news and research data | Continuously available          |
| Teplitz et al     | USA     | Range 21–77                       | N/R                                    | In person              | Support group meeting facilitated by ICD nurse, cardiac nurse and expert group facilitator. Includes presentations and Q&A session | 6 per year                     |

ICD, implantable cardioverter defibrillator; Q&A, question and answer.

Figure 2 Effect of ICD support groups on mental well-being. Forest plot for change in measure of mental well-being in patients with ICD attending a support group compared to usual care. CI, confidence interval.
Table 5  Quality assessment using the Mixed-Methods Appraisal Tool

| Author                  | Q1   | Q2   | 1.1  | 1.2  | 1.3  | 1.4  | 1.5  | For all: Q1: Are there clear research questions? |
|-------------------------|------|------|------|------|------|------|------|-------------------------------------------------|
| Molchany and Peterson   | Y    | Y    | N    | N    | N    | N    | N    | Y                                               |
| Serber et al            | Y    | Y    | Y    | Y    | U    | N    | N    | U                                               |
| Williams et al          | Y    | Y    | Y    | Y    | Y    | Y    | Y    | Y                                               |
| Dickerson et al         | Y    | Y    | Y    | Y    | Y    | Y    | Y    | Y                                               |
| Dickerson et al         | Y    | Y    | Y    | Y    | Y    | Y    | Y    | Y                                               |
| Dickerson              | Y    | Y    | Y    | Y    | Y    | Y    | Y    | Y                                               |
| Teplitz et al           | N    | U    | U    | U    | U    | Y    | U    | Y                                               |

| Author                  | Q1   | Q2   | 2.1  | 2.2  | 2.3  | 2.4  | 2.5  | Quantitative randomised controlled trial Q1: Is randomisation appropriately performed? |
|-------------------------|------|------|------|------|------|------|------|-------------------------------------------------|
| Yardimci and Mert       | Y    | Y    | Y    | Y    | Y    | Y    | U    | Y                                               |

| Author                  | Q1   | Q2   | 3.1  | 3.2  | 3.3  | 3.4  | 3.5  | Quantitative non-randomised Q1: Are the participants representative of the target population? |
|-------------------------|------|------|------|------|------|------|------|-------------------------------------------------|
| Molchany and Peterson   | Y    | Y    | Y    | Y    | Y    | Y    | Y    | Y                                               |
| Myers and James         | Y    | Y    | Y    | Y    | Y    | Y    | Y    | Y                                               |
| Dickerson et al         | Y    | Y    | Y    | Y    | Y    | Y    | Y    | Y                                               |

| Author                  | Q1   | Q2   | 4.1  | 4.2  | 4.3  | 4.4  | 4.5  | Quantitative descriptive Q1: Is the sampling strategy relevant to address the research question? |
|-------------------------|------|------|------|------|------|------|------|-------------------------------------------------|
| Serber et al            | Y    | Y    | Y    | Y    | U    | Y    | Y    | Y                                               |
year the dog wouldn’t go near him … we had a lot of laughs in there. (40, p92)

Online support groups also provided an opportunity to benefit from this friendship.39

Benefits and challenges of attending support groups

Two sub-themes were identified: sharing experiences and support group format.

Sharing experiences

The opportunity to share and compare experiences of life with an ICD is a key perceived benefit of attending a patient support group.39 40 42 Hearing that others felt the same about their life with an ICD provided validation of their own feelings,40 which in turn facilitated healing and acceptance.42 Attending support groups also provided reassurance and promoted acceptance of their ICD by seeing others lead a ‘normal’ life and coping with the uncertainty created by their heart condition and device.41 Information gained from fellow ICD recipients was more credible than that from healthcare providers, who can talk theory but not from experience.

After hours of bombarding my HCP with questions, you feel something missing; they know what you have, but they are just not going through it themselves; you need people that you can relate to. (39, p162)

Support group format

There was considerable variation in meeting frequency between the included studies (table 4). Most patients had a preference for at least quarterly meetings.42 All the in-person support groups were facilitated by HCPs—most often a specialist nurse—and expert speakers to provide education.42 Not all studies commented on the role of HCPs; only Dickerson et al reported the presence of an HCP at in-person meetings as being essential.40 Dickerson et al facilitated live streaming of in-person group meetings over the internet to address the barrier of attending due to accessibility; in-person attendees found this acceptable, however, the experience of remote attendance was not investigated.39

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DISCUSSION

The findings from our meta-analysis suggest that support groups have no significant effect on objectively measured mental well-being. However, the qualitative analysis suggests that patients do perceive a benefit from support group attendance in terms of managing fears through positive role modelling and accepting life with their ICD.

4.5. Is the statistical analysis appropriate to answer the research question?

Author Q1 Q2 5.1 5.2 5.3 5.4 5.5 Mixed-methods
Serber et al38 Y Y U N N Y U
Molchan and Peterson37 Y Y N U U Y N

Colour used for visual representation of quality: Green, met quality criteria; Amber, unclear if met quality criteria; Red, did not meet quality criteria N, No; U, Unclear ; Y, Yes.

Table 5 Continued
This may be because mental well-being is more than the absence of mental illness, and our meta-analysis predominantly included measures of anxiety.

The present study found that self-selected attendees have higher trait anxiety and lower social support than non-attendees with increased anxiety over time, possibly due to facing an issue previously avoided. Some patients preferred not to attend support groups as they did not want to be reminded about their ICD. In contrast to existing literature our study found no relationship between shock frequency and QoL, but patients did report that fear of shocks is the source of anxiety.
their anxiety. Support groups help to relieve this anxiety by fostering a sense of belonging and providing reassurance that there is life after ICD shocks. Positive role modelling from other attendees and sharing stories with other patients also relieves fear and anxiety in a way HCPs cannot. The lack of a significant effect on mental well-being demonstrated by the quantitative data may be attributable to the fact that the majority of included quantitative studies were observational with self-selected support group attendees, while a usual care comparison group may include patients with lower existing anxiety.

However, the single RCT also did not show reduction in anxiety over time in support group attendees. An alternative explanation is the use of general anxiety and QoL measures that may not be sensitive to the specific fears experienced by ICD patients. The use of different outcome measures to estimate mental well-being is a shortcoming of our meta-analysis, however, it highlights the lack of good quality quantitative data in this important topic.

The present study shows that sharing experiences is key to facilitating device acceptance, a consistent finding for in-person and online support groups. Gaining information is also an important benefit of support groups, although patients reported that they found information and understanding from fellow attendees more credible than that from HCPs. This suggests that support groups should prioritise patient-to-patient communication. Despite this finding, all in-person support groups used a HCP to provide information and education. The online support offered in these studies was in the form of web-based written forums, with the exception of one web-cast group meeting. The increased availability and use of video-conferencing technology since the COVID-19 pandemic has made remote meetings a viable option and provides the convenience of online meetings alongside the opportunity for patient-to-patient communication and HCP involvement. None of the reported studies conducted a comparison of in-person and online support. Future research could help guide the most efficient format for support groups, including use of HCP time and personnel and the delivery of online and in-person groups.

Most included studies were based in the USA, and it is striking that no Western European studies were found. A recent UK study commented that while there is interest in patient support groups, there are not many. Perhaps even more important is the fact that ICD implant rates in the USA have historically been 4–5 times higher than in Europe. This highlights the need for further research into and implementation of patient support groups in Europe.

Another area for future research is comparing the support needs of patients with ICDs for primary or secondary prevention of SCD. No data were available regarding participant ICD implant indications, however, the dates of most included studies signifies participants will have had ICDs for secondary prevention of SCD, whereas most implants are now primary prevention. Our data showed that patients have a fear of death and of shocks; as survivors of cardiac arrest, secondary prevention patients will have had different experiences leading to these fears compared with patients with ICDs implanted for primary prevention. As sharing experiences appears to be an important benefit of support groups, future research could explore whether primary and secondary prevention patients have sufficiently similar experiences to support each other.

Our mixed-methods systematic review has strengths and limitations. It was inclusive in terms of design, outcomes and publication status and dates. The screening and quality assessment was robust, with clear a priori definitions of the intervention of interest and outcomes provided. There was limited opportunity for meta-analysis from the quantitative data as there was no quantitative data regarding depression, device acceptance, or group format, despite these being important themes identified in the qualitative analysis.

In conclusion, this first mixed-methods systematic review and meta-analysis shows that while there is currently no quantitative evidence that ICD support groups have a significant beneficial effect on mental well-being, qualitative data show that patient support groups...
are perceived as beneficial by attendees. This suggests that we need other quantitative measures to assess the benefits of support groups for mental well-being. Attendees value the opportunity to share their experiences which helps them to accept their new life with an ICD. Further research is recommended into the optimal format of support groups, level of involvement of HCPs, and whether primary and secondary prevention ICD patients have different supportive needs.

**Contributors** KHS, PJP and MA designed the study and took overall responsibility for its content; KHS, PAC and MA assessed study eligibility; KHS, PAC and KC assessed study quality; KHS, HD and MA analysed the data; KHS, HD, MA and KC contributed to the data interpretation; all authors contributed to the drafting of the manuscript and approved the final version to be published. KHS acts as guarantor for the study.

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