openheart

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

Katie H Sanders ,[1,2] Panagiota Anna Chousou,[1,3] Kathryn Carver,[1] Peter J Pugh,[1] Hans Degens,[2,4] May Azzawi[2]

To cite: Sanders KH, Chousou PA, Carver K, *et al*. Benefits of support groups for patients living with implantable cardioverter defibrillators: a mixed-methods systematic review and meta-analysis. *Open Heart* 2022;**9**:e002021. doi:10.1136/openhrt-2022-002021

Received 19 April 2022
Accepted 9 August 2022

[1]Cardiology, Cambridge University Hospitals NHS Foundation Trust, Cambridge, UK
[2]Department of Life Sciences, Manchester Metropolitan University, Manchester, UK
[3]Norwich Medical School, University of East Anglia, Norwich, UK
[4]Lithuanian Sports University, Kaunas, Lithuania

Correspondence to
Dr May Azzawi; m.azzawi@mmu.ac.uk

ABSTRACT

Background Patients with implantable cardioverter defibrillators (ICD) 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 could 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).[1] 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.[2 3]

Patients with ICDs experience anxiety and depression.[4 5] This may be present in patients with or without ICD-delivered shocks, but is increased by higher incidence of shocks.[6] The delivery of a shock to restore sinus rhythm has been shown to cause a transient reduction in quality of life (QoL).[7] Anxiety and reduced QoL are associated with increased readmissions and 1-year mortality for ICD patients.[8] It has also been suggested that there is a correlation between anxiety and the occurrence of arrhythmia.[9]

A range of psychological and educational interventions to improve psychological outcomes for patients with ICDs have been investigated.[10–16] 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[17] and high-profile cardiac charities[18 19] 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.[20] Support groups also provide an option for supportive care using limited healthcare resources.[21]

There are many support groups for patients with chronic conditions such as cancer and heart failure.[22–24] 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.[22–24] 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.[25]

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.[20] 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.[26] 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.

Table 1 Medline search strategy

1	(((single or dual or biventricular) adj defibrillator*) OR implantable cardioverter defibrillator OR implantable defibrillator* OR implantable cardioverter-defibrillator*)	14 581
2	Defibrillators, Implantable/	17 403
3	1 OR 2	22 459
4	(support group* OR peer support OR peer counselling OR self-help group* OR self help group* OR education* support OR psychosocial support OR patient mentor*)	25 883
5	Self-Help Groups/	9314
6	4 OR 5	25 883
7	3 AND 6	43

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)[27] was used by two independent reviewers (KHS and PAC/KC) 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.[28] 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 methods[31] 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 studies[39–42] and one service evaluation.[43]

One study was based in Australia[42] and one in Turkey.[34] The remainder were from the USA. In all studies the support group attendees were predominantly male (range

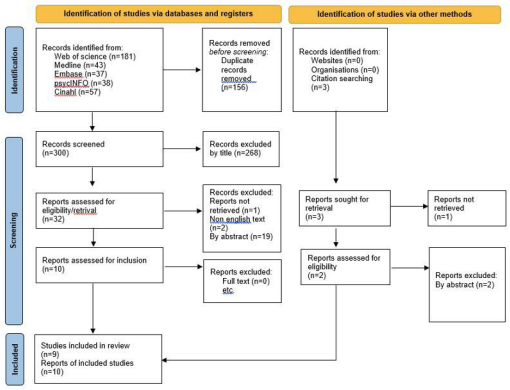

Figure 1 Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) 2020 flow diagram.

53%–91%). The support groups varied considerably in terms of attendee age, format and frequency (table 4).

Four papers[34–37] 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 one[37] reported only a range. We contacted the authors for this information, but the raw data was no longer available.

Seven papers[37–43] 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 studies[34 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 studies[34 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]

Table 2 Summary of characteristics and results from included quantitative studies

Author country	Research aims	Research design	Sample characteristics	Outcome measures	Instruments	Key results	Key findings
Yardımcı and Mert[34] 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 14.56, 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[36] 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 ↓satisfaction 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*[35] 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 (QLI:CV). 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[37] 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 (26 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 attendees 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 20.55, 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

Continued

Table 2 Continued

Author country	Research aims	Research design	Sample characteristics	Outcome measures	Instruments	Key results	Key findings
Serber *et al*[38] 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. 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, 0% somewhat 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.

Attendees had significantly higher trait anxiety than non-attendees,[36] although this was not significant for state anxiety.[37]

Quality of life

QoL was measured in two quantitative studies using the SF-36[34] and QLI.[35] 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.[34] Age and frequency of shocks were not related to QLI, however, greater comorbidity was found to correlate with reduced QoL.[35]

Social support

Social support was not identified as an outcome a priori for this review but was measured in three quantitative studies[34 36 37] and was seen in the qualitative data; it was therefore included in the analysis to assess whether this contributes to the benefit of support groups.

Social support was measured using Saracon's 6-item Social Support questionnaire,[36] in sub-dimensions of the Medical Outcomes Study survey[37] and SF-36.[34] Support group attendance was associated with lower satisfaction with social support.[36] However, a descriptive study found support group attendees experienced a higher level and value of support than non-attendees.[35] There was no difference between groups in social functioning,[34 37] where social functioning increased over time in both groups in an RCT.[34]

Effect of support groups on mental well-being

The effect of support groups on mental well-being was examined by normalising anxiety and QoL outcomes to the average control value (Fig. 2). The absolute data used in this meta-analysis are shown in Table 7. The standardised mean difference between intervention and control groups was 0.02 (95% CI −0.2 to 0.23). The support group attendees scores were not significantly higher than the control group average, z=0.16, p=0.87, indicating that attending support groups had no significant effect on mental well-being for patients with ICDs.

Qualitative analysis

Anxiety and depression

Patients reported that fear of death and of ICD shocks were the source of their anxiety.[37 39–41 43]

> 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.[39] Patients also felt that positive role modelling

Table 3 Summary of characteristics and results from included qualitative studies

Author country	Research aims	Research design	Population	Outcome measures	Instruments	Key findings
Molchany and Peterson[37] 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*[38] 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*[42] 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*[40] 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

Table 3 Continued

Author country	Research aims	Research design	Population	Outcome measures	Instruments	Key findings
Dickerson *et al*[40] USA	To explore the common themes and shared meanings of internet discussions on an informal public electronic bulletin board for persons with ICDs	Qualitative Heideggarian 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[39] USA	To explore the practical knowledge gained from internet use by implantable cardioverter defibrillator (ICD) recipients	Qualitative Heideggarian 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*[43] 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.

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[34] 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[36] 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*[35] 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[37] 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*[38] 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*[42] 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*[40] 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*[41] 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[39] 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*[43] 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.

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,[37] affecting relationships[43] and preventing acceptance of their ICD.[41] Encouragement from other group members to resume normal life activities helped patients manage their depression.[37 43]

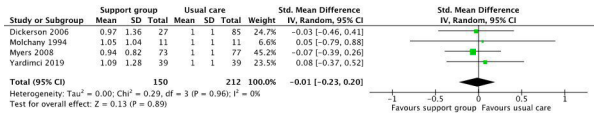

Figure 2 Effect of ICD support groups on mental well-being. Forest plot for change in measure of mental well-being in patients with ICD attending a support group compared to usual care. CI, confidence interval.

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 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[37]	Y	Y	N	N	N	N	N		Q2: Do the collected data allow to address the research questions?
Serber *et al*[38]	Y	Y	Y	Y	U	N	U		**Qualitative**
Williams *et al*[42]	Y	Y	Y	Y	Y	Y	Y		1.1. Is the qualitative approach appropriate to answer the research question?
Dickerson *et al*[40]	Y	Y	Y	Y	Y	Y	Y		1.2. Are the qualitative data collection methods adequate to address the research question?
Dickerson *et al*[41]	Y	Y	Y	Y	Y	Y	Y		1.3. Are the findings adequately derived from the data?
Dickerson[39]	Y	Y	Y	Y	Y	Y	Y		1.4. Is the interpretation of results sufficiently substantiated by data?
Teplitz *et al*[43]	N	U	U	U	U	Y	U		1.5. Is there coherence between qualitative data sources, collection, analysis and interpretation?
Author	Q1	Q2	2.1	2.2	2.3	2.4	2.5		**Quantitative randomised controlled trial**
Yardimci and Mert[34]	Y	Y	Y	Y	Y	Y	U		2.1. Is randomisation appropriately performed?
									2.2. Are the groups comparable at baseline?
									2.3. Are there complete outcome data?
									2.4. Are outcome assessors blinded to the intervention provided?
									2.5. Did the participants adhere to the assigned intervention?
Author	Q1	Q2	3.1	3.2	3.3	3.4	3.5		**Quantitative non-randomised**
Molchany and Peterson[37]	Y	Y	Y	Y	Y	N	Y		3.1. Are the participants representative of the target population?
Myers and James[36]	Y	Y	Y	Y	Y	Y	Y		3.2. Are measurements appropriate regarding both the outcome and intervention (or exposure)?
Dickerson *et al*[35]	Y	Y	Y	Y	Y	Y	Y		3.3. Are there complete outcome data?
									3.4. Are the confounders accounted for in the design and analysis?
									3.5. During the study period, is the intervention administered (or exposure occurred) as intended?
Author	Q1	Q2	4.1	4.2	4.3	4.4	4.5		**Quantitative descriptive**
Serber *et al*[38]	Y	Y	Y	Y	U	Y	Y		4.1. Is the sampling strategy relevant to address the research question?
									4.2. Is the sample representative of the target population?
									4.3. Are the measurements appropriate?
									4.4. Is the risk of non-response bias low?

Continued

Table 5 Continued

Author	Q1	Q2	5.1	5.2	5.3	5.4	5.5
4.5. Is the statistical analysis appropriate to answer the research question?							
Mixed-methods							
Serber *et al*[38]	Y	Y	U	N	N	Y	U
5.1. Is there an adequate rationale for using a mixed-methods design to address the research question?							
Molchany and Peterson[37]	Y	Y	N	U	U	N	N
5.2. Are the different components of the study effectively integrated to answer the research question?							
5.3. Are the outputs of the integration of qualitative and quantitative components adequately interpreted?							
5.4. Are divergences and inconsistencies between quantitative and qualitative results adequately addressed?							
5.5. Do the different components of the study adhere to the quality criteria of each tradition of the methods involved?							

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.

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.[39–41 43] 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), and patients reported 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.[36 38 42 43] 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]

Williams *et al* reported that travel time from rural locations was a major barrier to group attendance, while others did not attend as they did not feel in need of support, did not want to be reminded about their ICD, or perceived that they did not fit in the group due to age or sex.[42] Serber *et al* initiated 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.[38] Patients reported that the benefits of online support were ease of access,[39] and timing, as online support was available day and night.[41]

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.

Table 6 Integrated synthesis of outcomes from ICD support groups

Quantitative data	Interpretation	Main pillar	Interpretation	Qualitative data
Anxiety and depression				
Measures: STAI, VAS, FSAS	Anxiety measured by STAI decreases over time in all groups, however, VAS-A increased. Support group attendees tend to be more anxious than non-attendees in observational studies. STAI, VAS baseline measurements were in normal range. FSAS scores were average for the population	Variety of measures used, inconsistent results across studies. Optimal measure for anxiety in ICD patients is unclear. Support group attendance may need targeting to patients with pre-existing anxiety about their ICD. Knowledge acquisition and sharing experiences helps patients control their fear and anxiety	Fear of death and ICD shocks are the two sources of anxiety. Support groups may help manage/control fear and anxiety through sharing of experience, knowledge and coping mechanisms. Positive role modelling provides reassurance that there is life after shocks. Patients have more confidence in support and information from fellow recipients compared with healthcare professionals and other support persons. Single perspective that support groups act as unwanted reminder of ICD implant	Measures: virtual and in-person focus groups, semi-structured interviews, email interviews, observation of meetings and group leader's notes, observation of online postings
Silence		Effect of support groups on depression in ICD patients is unclear	Support groups may help manage depression through promoting hope from positive role models. Support groups can encourage patients to resume normal activity, improving acceptance of ICD	Measures: in-person focus groups, semi-structured interviews, observation of meetings, observation of online postings
Quality of life				
Measures: SF-36, QLI, MOS	No significant difference in overall QoL scores. Significant difference in subscales of social functioning, role-physical, mental health, vitality and bodily pain	Variety of general measures of QoL used, no evidence for overall improvement. Support group attendance may help improve specific sub-dimensions of QoL. Data suggest informational support is key to improving QoL	Support group attendance helps find ways to live with ICD and deal with limitations through improving technical knowledge and understanding of the ICD, encouraging return to normal activities. Single perspective that gender-specific meetings may be helpful to cope with lifestyle changes	Measures: virtual and in-person focus groups, semi-structured interviews, email interviews, observation of meetings and group leader's notes, observation of online postings
Social support and functioning				
Measures: subscales of SF-36 and MOS, Saracon's Social Support Questionnaire	Conflicting data regarding association between support group attendance and social support. No difference in social functioning between attendees and non-attendees but improves over time in both groups	Variety of measures used, inconsistent results across studies. Existing social support may not predict benefit from support group due to lack of shared experience. Online and in-person groups provide social support	Support groups provide access to social support with shared experience which is different to existing support. Online support groups may provide similar benefits in terms of social support, and are more easily and frequently accessible	Measures: virtual and in-person focus groups, semi-structured interviews, email interviews, observation of meetings, observation of online postings
Patient perceived benefits and barriers to attending support groups				
Silence		Optimal support group format is unclear. Support group attendees report significant benefits from attending; sharing experiences is key to facilitating device acceptance. Optimal measures for patient perceived benefit are unclear	Shared patient experience and humour is seen as providing more credible information than that from HCPs, and facilitates acceptance of ICD. Single perspective that HCP facilitation of a support group is essential. Single perspective that barriers to attendance include travel distance, gender and age differences. Online support can provide more accessible support than in-person support groups	Measures: virtual and in-person focus groups, semi-structured interviews, email interviews, observation of meetings and group leader's notes, observation of online postings

FSAS, Florida Shock Anxiety Scale; HCP, healthcare professional; ICD, implantable cardioverter defibrillator; MOS, Medical Outcomes Study; QLI, Quality of Life Index; QoL, quality of life; SF-36, Short-Form 36; STAI, State-Trait Anxiety Index; VAS, Visual Analogue Scale.

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[36] with increased anxiety over time[37] 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.[42] 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

Table 7 Quantitative data included in analysis

Study	QoL measure	Support group attendees		Support group non-attendees		
		Mean±SD	Total participants	Mean±SD	Total participants	
Molchany and Peterson[37]	SAI (lower score better)	34.8±11.26	11	36.4±11.67	11	p=0.399
Dickerson *et al*[40]	QLI (higher score better)	23.7±3.6	27	23±4.9	85	p=0.770
Myers and James[36]	SAI (lower score better)	35.21±12.94	73	33.1±10.57	77	p=0.230
Yardimci and Mert[34]	FSAS (lower score better)	13.3±6.13	39	16.78±10.62	39	p=0.083
Yardimci and Mert[34]	SF-36 physical component	52.02±9.45	39	47.46±13.82	39	p=0.139
Yardimci and Mert[34]	SF-36 mental component	43.29±9.02	39	44.69±8.08	39	p=0.361

FSAS, Florida Shock Anxiety Scale; QLI, Quality of Life Index; QoL, quality of life; SAI, State Anxiety Index; SF-36, Short Form 36.

their anxiety. Support groups help to relieve this anxiety by fostering a sense of belonging[41] and providing reassurance that there is life after ICD shocks.[40] Positive role modelling from other attendees and sharing stories with other patients also relieves fear and anxiety in a way HCPs cannot.[40 41]

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.[36] However, the single RCT[34] 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.[39 41 42] 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.[38] 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[44] 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.[45] This highlights the need for further research in, 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.[46] 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.

Funding This review was funded by the National School of Healthcare Science under its Higher Specialist Scientist Training Programme; KHS is a funded Higher Specialist Scientist Trainee. The funder had no role in the collection, analysis and interpretation of data; the funder had no role in the writing of and decision to publish this review. The views expressed are those of the author(s) and not necessarily those of the National School of Healthcare Science.

Competing interests None declared.

Patient consent for publication Not applicable.

Provenance and peer review Not commissioned; externally peer reviewed.

Data availability statement Data sharing not applicable as no datasets generated and/or analysed for this study.

ORCID iD

Katie H Sanders http://orcid.org/0000-0002-4829-0583

REFERENCES

1 Santini M, Lavalle C, Ricci RP. Primary and secondary prevention of sudden cardiac death: who should get an ICD? *Heart* 2007;93:1478–83.
2 Cunningham AD, Plummer CJ, McComb JM, *et al*. The implantable cardioverter-defibrillator: postcode prescribing in the UK 1998-2002. *Heart* 2005;91:1280–3.
3 Murgatroyd F, Dayer M. National Audit of Cardiac Rhythm Management (NACRM) [Internet], 2021. National Institute for Cardiovascular Outcomes Research. Available: nicor.org.uk/cardiac-rhythm-management-arrhythmia-audit/
4 Berg SK, Herning M, Thygesen LC, *et al*. Do patients with ICD who report anxiety symptoms on hospital anxiety and depression scale suffer from anxiety? *J Psychosom Res* 2019;121:100–4.
5 Magyar-Russell G, Thombs BD, Cai JX, *et al*. The prevalence of anxiety and depression in adults with implantable cardioverter defibrillators: a systematic review. *J Psychosom Res* 2011;71:223–31.
6 Perini AP, Kutyifa V, Veazie P, *et al*. Effects of implantable cardioverter/defibrillator shock and antitachycardia pacing on anxiety and quality of life: a MADIT-RIT substudy. *Am Heart J* 2017;189:75–84.
7 da Silva KR, Costa R, Rodrigues CG, *et al*. Quality of life in patients with implantable cardioverter-defibrillator: systematic review of randomized controlled trials. *Eur J Cardiovasc Nurs* 2018;17:196–206.
8 Berg SK, Rasmussen TB, Mols RE, *et al*. Both mental and physical health predicts one year mortality and readmissions in patients with implantable cardioverter defibrillators: findings from the National DenHeart study. *Eur J Cardiovasc Nurs* 2019;18:96–105.
9 Hoogwegt MT, Pedersen SS, DAMJ T, *et al*. Relation between emotional distress and heart rate variability in patients with an implantable cardioverter-defibrillator: emotional distress and HRV in ICD patients. *Psychophysiology* 2014;51:187–96.
10 Badger JM, Morris PL. Observations of a support group for automatic implantable cardioverter-defibrillator recipients and their spouses. *Heart Lung* 1989;18:238–43.
11 Sears SF, Sowell LDV, Kuhl EA, *et al*. The ICD shock and stress management program: a randomized trial of psychosocial treatment to optimize quality of life in ICD patients. *Pacing Clin Electrophysiol* 2007;30:858–64.
12 Ford J, Rosman L, Wuensch K, *et al*. Cognitive-Behavioral treatment of posttraumatic stress in patients with implantable cardioverter defibrillators: results from a randomized controlled trial. *J Trauma Stress* 2016;29:388–92.
13 Irvine J, Firestone J, Ong L, *et al*. A randomized controlled trial of cognitive behavior therapy tailored to psychological adaptation to an implantable cardioverter defibrillator. *Psychosom Med* 2011;73:226–33.
14 Dunbar SB, Langberg JJ, Reilly CM, *et al*. Effect of a psychoeducational intervention on depression, anxiety, and health resource use in implantable cardioverter defibrillator patients. *Pacing Clin Electrophysiol* 2009;32:1259–71.
15 Qintar M, George JJ, Panko M, *et al*. A prospective study of anxiety in ICD patients with a pilot randomized controlled trial of cognitive behavioral therapy for patients with moderate to severe anxiety. *J Interv Card Electrophysiol* 2015;43:65–75.
16 Nielsen K, Zwisler A, Taylor R, *et al*. Exercise-based cardiac rehabilitation for adult patients with an implantable cardioverter defibrillator (review). *Cochrane Database Syst Rev* 2019.
17 British Heart Rhythm Society. *Clinical standards and guidelines for the follow up of cardiac implantable electronic devices (CIEDs) for cardiac rhythm management*. Vol. 21, 2020: 1–9.
18 Arrhythmia Alliance. Guidelines to establish a local support group [Internet], 2017. Available: https://www.heartrhythmalliance.org/aa/uk/support-groups
19 Support groups - British Heart Foundation [Internet]. Available: https://www.bhf.org.uk/informationsupport/support/support-groups-and-online-communities [Accessed 08 Oct 2021].
20 Delisle VC, Gumuchian ST, Rice DB, *et al*. Perceived benefits and factors that influence the ability to establish and maintain patient support groups in rare diseases: a scoping review. *Patient* 2017;10:283–93.
21 Proietti R, Manzoni GM, Pietrabissa G, eds. *Social and Cognitive Aspects of Implantable Cardiac Devices*. Cham, Switzerland: Springer, 2017.
22 Devitt B, Hatton A, Baravelli C, *et al*. What should a support program for people with lung cancer look like? differing attitudes of patients and support group facilitators. *J Thorac Oncol* 2010;5:1227–32.
23 Mallya S, Daniels M, Kanter C, *et al*. A qualitative analysis of the benefits and barriers of support groups for patients with brain tumours and their caregivers. *Support Care Cancer* 2020;28. doi:10.1007/s00520-019-05069-5. [Epub ahead of print: Available from].
24 Lockhart E, Foreman J, Mase R, *et al*. Heart failure patients' experiences of a self-management peer support program: A qualitative study. *Heart Lung* 2014;43:292–8.
25 Page MJ, McKenzie JE, Bossuyt PM, *et al*. The PRISMA 2020 statement: an updated guideline for reporting systematic reviews. *PLoS Med* 2021;18:e1003583.
26 Galderisi S, Heinz A, Kastrup M, *et al*. Toward a new definition of mental health. *World Psychiatry* 2015;14:231–3.
27 Hong Q, Pluye P, bregues S F, *et al*. Mixed methods appraisal tool (MMAT), version 2018. *User guide. McGill* 2018:1–11.
28 Manager R. RevMan) [Computer program]. Version 5.4. *The Cochrane Collection* 2020.
29 Sin NL, Lyubomirsky S. Enhancing well-being and alleviating depressive symptoms with positive psychology interventions: a practice-friendly meta-analysis. *J Clin Psychol* 2009;65:467–87.
30 Carolan S, Harris PR, Cavanagh K. Improving employee well-being and effectiveness: systematic review and meta-analysis of web-based psychological interventions delivered in the workplace. *J Med Internet Res* 2017;19:e271.
31 Thomas J, Harden A. Methods for the thematic synthesis of qualitative research in systematic reviews. *BMC Med Res Methodol* 2008;8:45.
32 Johnson RE, Grove AL, Clarke A. Pillar integration process: a joint display technique to integrate data in mixed methods research. *J Mix Methods Res* 2019;13:301–20.
33 Forman J, Murtagh E, Cheung J, *et al*. Developing an implantable cardioverter defibrillator patient education program: preliminary findings of a knowledge translation project. *Eur J Cardiovasc Nurs* 2021;20:zvab060.146.

34 Yardımcı T, Mert H. Web-Based intervention to improve implantable cardioverter defibrillator patients' shock-related anxiety and quality of life: a randomized controlled trial. *Clin Nurs Res* 2019;28:150–64.
35 Dickerson SS, Wu Y-WB, Kennedy MC. A CNS-facilitated ICD support group: a clinical project evaluation. *Clin Nurse Spec* 2006;20:146–53.
36 Myers GM, James GD. Social support, anxiety, and support group participation in patients with an implantable cardioverter defibrillator. *Prog Cardiovasc Nurs* 2008;23:160–7.
37 Molchany CA, Peterson KA. The psychosocial effects of support group intervention on AICD recipients and their significant others. *Prog Cardiovasc Nurs* 1994;9:23–9.
38 Serber ER, Finch NJ, Afrin LB, *et al*. Using a webcast support service: experiences of in-person Attendees of an implantable cardioverter defibrillator support group. *Heart Lung* 2010;39:94–104.
39 Dickerson SS. Technology--patient interactions: Internet use for gaining a healthy context for living with an implantable cardioverter defibrillator. *Heart Lung* 2005;34:157–68.
40 Dickerson SS, Posluszny M, Kennedy MC. Help seeking in a support group for recipients of implantable cardioverter defibrillators and their support persons. *Heart Lung* 2000;29:87–96.
41 Dickerson SS, Flaig DM, Kennedy MC. Therapeutic connection: help seeking on the Internet for persons with implantable cardioverter defibrillators. *Heart Lung* 2000;29:248–55.
42 Williams AM, Young J, Nikoletti S, *et al*. Reasons for attending and not attending a support group for recipients of implantable cardioverter defibrillators and their carers. *Int J Nurs Pract* 2004;10:127–33.
43 Teplitz L, Egenes KJ, Brask L. Life after sudden death: the development of a support group for automatic implantable cardioverter-defibrillator patients. *J Cardiovasc Nurs* 1990;4:20–32.
44 Murray K, Buttigieg K, Todd M, *et al*. Delivering an efficient and effective support group for patients with implantable cardioverter-defibrillators (ICDs): patient perspectives of key concerns and predictors of inclination to attend. *BMC Health Serv Res* 2021;21:745.
45 John Camm A, Nisam S. European utilization of the implantable defibrillator: has 10 years changed the 'enigma'? *Europace* 2010;12:1063–9.
46 Haugaa KH, Tilz R, Boveda S, *et al*. Implantable cardioverter defibrillator use for primary prevention in ischaemic and non-ischaemic heart disease—indications in the post-DANISH trial era: results of the European heart rhythm association survey. *EP Eur* 2017;19:660–4.