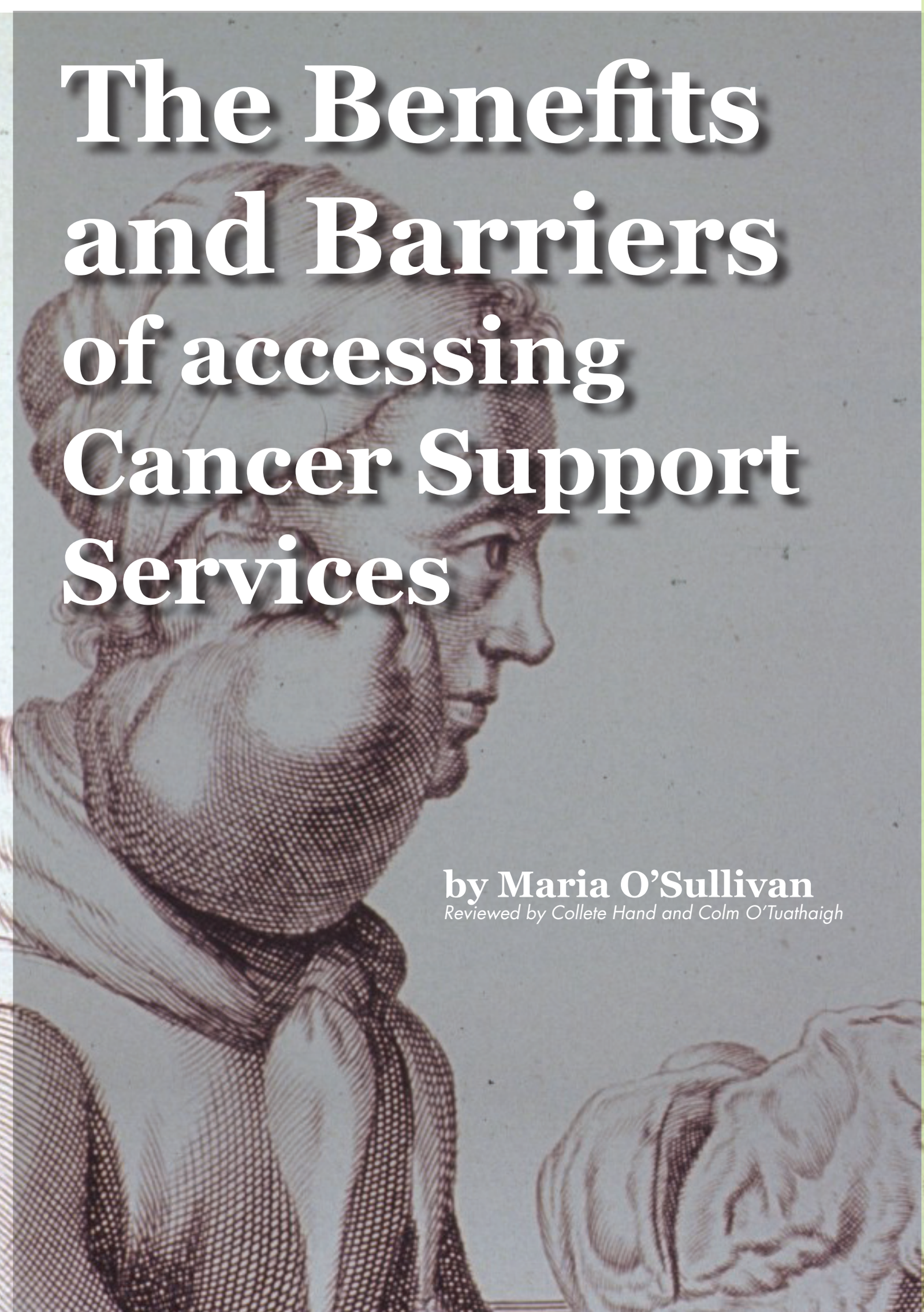
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UCC
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The Benefits and Barriers of accessing Cancer Support Services



by Maria O'Sullivan
Reviewed by Collete Hand and Colm O'Tuathaigh

Abstract

Introduction

Cancer is a substantial cause of morbidity and mortality worldwide. In Ireland, rising cancer incidence means that the burden on society will continue to increase. Recent recognition of the large impact of psychological distress on patients with cancer has led to suggestions to use support centres to mitigate this distress. Thus, the benefits of participation and barriers to attendance must be explored.

Aims & Objectives

To systematically review scientific literature and determine the:
(i) Sociodemographic composition of cancer support centres.
(ii) Benefits of support services to patients with cancer.
(iii) Barriers/facilitators to support centre attendance.

Methods

Electronic searches were carried out PubMed and the Cumulative Index to Nursing and Allied Health Literature (CINHAL) databases using key words addressing the research question. Ten articles were selected and critically appraised.

Results

A summary of article results showed that while various groups remain underrepresented in support centres, new evidence suggests this may be changing. Increased support service attendance was linked to greater benefits. No change in anxiety or depression with attendance were seen. Barriers to attendance were identified.

Conclusions

The literature showed benefits to support services, but long term benefits must be further investigated. Future research quantitatively assessing benefits of support services, using validated assessment instruments are necessary. Psychological benefits of participation are still unclear. Validated questionnaires to assess the barriers to attendance must be developed. Lastly, there is a lack of studies on the benefits of and barriers to support services participation in the Irish population.

Introduction

Cancer is a leading cause of death and disability worldwide, accounting for almost 1 in 6 deaths [1]. In Ireland, cancer was the second most common cause of death [2]. The number of Irish cancer cases will rise by 84% for females and 107% for males between 2010 and 2040 [3]. Thus, cancer will remain a national and global health priority. Psychological distress is commonly experienced by patients with cancer. This distress may manifest at various stages [4-7]. Curative cancer treatment may not meet the needs of patients completely, particularly their psychological needs. Previous studies have assessed the unmet needs of patients with cancer [8-10]. In Ireland, the National Cancer Strategy 2017-2026 deems psycho-social support as "essential" in the care of cancer patients and survivors [11]. The National Institute for Health and Care Excellence (NICE) guidelines on' Improving supportive and palliative care for adults with cancer' recommends support groups as a resource for patients with cancer [12].

Objectives

The objective of this systematic review is to evaluate the published literature from scientific databases to determine the:

i. Typical sociodemographic composition of cancer support centres, including underrepresented groups.
ii. Benefit of support services in patients with cancer.
iii. Barriers/facilitators to cancer support service participation.

Methods

Electronic searches were performed on the PubMed and CINAHL databases to attain literature corresponding to the research objectives.

1. Two articles were recommended by my project supervisor:

They pertained to two randomised control trials (RCT) looking at the benefits of support group interventions and were identified on the PubMed database [13, 14].

2. Forty-five articles were selected on PubMed using the following search equation:

(((Support group[Title]) AND Cancer [Title]) AND participation[Title]) OR ((Cancer support group*[Title]) AND benefit*)

Filters were added to the search: Articles since 2005 (reduction to 30 articles) and adults aged 19+ years (reduction to 22 articles).

The remaining articles were manually reviewed by reading titles and abstracts based on selection criteria. Main reasons for exclusion were the article focusing on:

i. Health professional/specialist/carer/group leaders' opinions on support groups
ii. Support group cost comparisons
iii. 'Lurkers' (i.e. users not actively participating) in online support groups.
iv. Specific minority group.

Next, any articles meeting the selection criteria without free full text available (18 articles) were excluded. Four PubMed articles were selected.

3. 67 articles were selected on CINAHL using the following search equation:

((TI Cancer support group*) AND (benefit)) OR ((TI Support group) AND (TI Cancer) AND (TI participation))

The same time period filter was applied (i.e. articles since 2005) with 46 results. The filter 'All Adults' brought the article total to 24.

17 were duplicates of articles from PubMed. Also excluded were articles focusing on: Spouse/siblings/parents

Articles without full free text available were removed after selection criteria application. Three CINAHL articles were selected.
Figure 1 and 2 show schematics of article selection from PubMed and CINAHL databases.

4. One article identified from screening reference section of other articles selected:

This was a longitudinal, cross-sectional study on barriers to support group attendance [15]

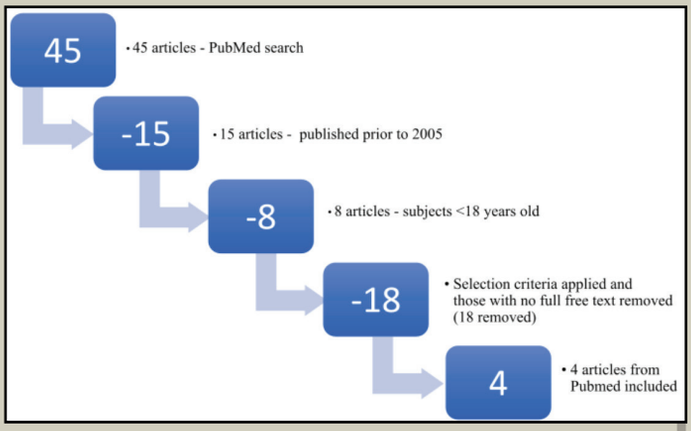


Figure 1:
Flow-chart depicting study selection for PubMed data-

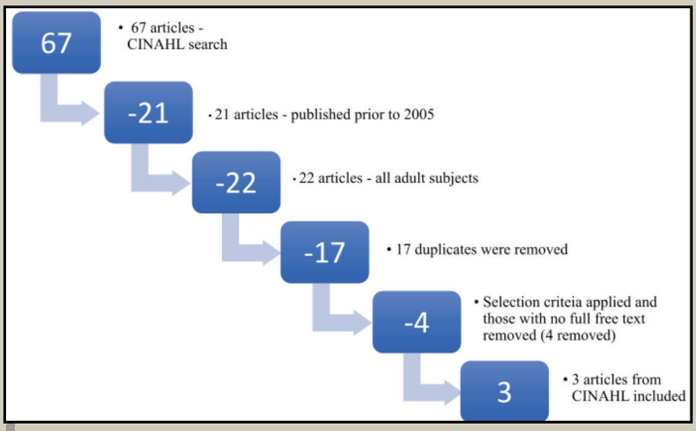


Figure 2:
Flow-chart depicting study selection for CINAHL data-

Selection crtiteria

See table 1. Ten remaining articles were summarised under the headings: objective, study type, methods, sample size, study population and selection criteria, key findings and strengths/limitations (Table 2). They were critically appraised using the Evidence-based librarianship (EBL) critical appraisal checklist tool. Validity scores were

determined (Table 3) {L., 2006 #243}[16].

Results

3.1 Result Summaries

Table 2 summarises article results. Box 1 demonstrates abbreviations used in Table 2.

3.2 Quality of studies

The EBL critical appraisal checklist tool was employed to compute section and overall validity scores. Table 3 section validity scores were calculated using the formula:
Validity Score = (Y) ÷ (Y + N +U). The overall validity score, was an average of the four section validity scores. Scores ≥75% imply validity.
Table 3: Section and Overall Validity Scores as calculated using the EBL Critical Appraisal Checklist

3.3 Sociodemographic composition of support groups

3.3.1 Overrepresented groups

Four cross-sectional studies assessed support group composition. Overrepresented parties, included those that are; young [22, 23], white/

Inclusion criteria:	Exclusion criteria:
- ≥18 years old	- <18 years old
- Articles in English	- Articles not in English
- Patients with cancer and cancer survivors	- Health professionals/specialists opinions on support services
- Studies after 2005	- Studies regarding support centre leaders
- Benefits of cancer support services	- Cost comparison for support service types
- Barriers to participation in cancer support services	- Studies involving family carers/caregivers/ spouses
- Sociodemographic composition of support services	- Studies regarding physical activity in patients with cancer
	- Studies looking at lurking in online cancer support services
	- Studies with primary focus on a certain ethnic/minority group

Table 1:
Selection Criteria

RCT	Randomised control trial
Non-RCT	Non-randomised control trial
QOL	Quality of life
HADS	Hospital Anxiety and Depression Scale
CRI	Coping Resources Inventory
FQ	Fatigue Questionnaire
Hx.	History

Box 1:
Abbreviations used in Table 2.

Caucasian [20, 21], female [20, 22], have a higher education level [21-23], higher income, are married, are employed [23], and those with breast cancer/multiple myeloma [21].

3.3.2 Underrepresented groups

A 2010 UK cross-sectional study [20], showed increased attendance in males/those of lower socioeconomic status, compared to previous studies [22].

3.4 Benefits of support groups participation

Eight studies assessed the benefits of support group attendance for patients with cancer.

3.4.1 Attendance Frequency

Two cross-sectional studies showed a positive correlation between attendance levels and level of perceived benefit [20, 21]. A longitudinal study showed that emotional well-being was related both to coping style and frequency of support group use. Frequent participation, particularly helped those approaching their emotions less actively [13].

3.4.2 Anxiety and depression

Two studies, one RCT and one non-RCT, showed no significant change in anxiety and depression, using the Hospital Anxiety and Depression Scale (HADS) [18, 19]. Similarly, a randomised longitudinal study, using the Center for Epidemiological Studies-Depression (CES-D) survey, showed no variation in depressive symptoms [17].

3.4.3 Health-related quality of life

A RCT showed that, health related quality of life was positively associated with the support group intervention [19]. Conversely, a descriptive cross-sectional study showed an increased health-related quality of life to be insignificant [23].

3.4.4. Quality of life

A RCT measuring quality of life showed a positive correlation with increased quality of life in the intervention group and negative correlation in the control group at 6 weeks [14]. This change returned to baseline at the study completion.

3.4.5. Other Benefits

i. Perceived psychological benefits greater in females than males [20].
ii. Decreased fatigue was positively associated with support group intervention [19].
iii. The moderated group was associated with increased participation when compared to the peer-led group [17].
iv. Support group intervention was positively associated with increased coping resources [18].

3.5 Barriers/ Facilitators to support group

participation

3.5.1 Barriers:

Two studies examined barriers to support group attendance for patients with cancer.

A longitudinal study of drop-outs and cross-sectional study of non-attendees showed that barriers differed between both groups [15]. It identified two different reactions in support groups drop-outs (i.e. positive or negative attitude towards support groups). Those with different attitudes had different reasons for drop-out.
A cross-sectional study looking at barriers to support group attendance cited similar reasons to those cited by Ussher et al [15], including geographical location and lack of awareness of support group existence [21].

3.5.2 Facilitators:

Two studies looked at the facilitators of support group attendance for patients with cancer.

3.5.1.1 Common facilitators

i. Facilitators included patients having family/ friends encourage or support their attendance [21, 22].

3.5.2.2 Other facilitators

i. Patients perception of support group benefit, actively coping, and having an insufficient support system for the patients' needs [22].
ii. Increased disease severity/stress due to illness [21].

Discussion

Table 2 details strengths and weaknesses of each study.

4.1 Sociodemographic composition of support groups

A 2011 cross-sectional study of the UK population contradicted results of similar previous studies. It showed an increased proportion of men/those of lower socioeconomic among attendees [20]. The authors hypothesised that this change in support groups composition may be due to new NICE guidelines introduced in 2004 [12]. Low response rate (29%), was a weaknesses of this study, which even in a large population, may affect validity. Despite support group composition appearing to change in recent studies, some sociodemographic groups remain underrepresented (e.g. males, minorities, low socioeconomic status). [20] This issue must be addressed to allow equally oppor-

Article	Population Validity Score (%)	Data collection Validity Score (%)	Study design Validity Score (%)	Results Validity Score (%)	Overall Validity Score (%)
Batenburg A. et al. (2014) [13]	0*	83	100	80	**66***
Osei D.K. et al. (2013) [14]	56*	100	100	67*	**81**
Klemm P. (2012) [17]	29*	83	100	80	**73***
Emilsson S. et al. (2012) [18]	71*	100	100	80	**88**
Björneklett H.G. (2012) [19]	78	83	100	67*	**82**
Stevinson C. et al. (2011) [20]	67*	80	100	80	**77**
Sherman A.C. et al. (2008) [21]	67*	80	80	80	**77**
Ussher J.M. et al. (2008) [15]	17*	50*	100	80	**62***
Grande G.E. et al. (2006) [22]	83	67*	100	80	**83**
Michalec B. (2006) [23]	67*	60*	80	100	**77**

***Not valid**

Table 3:
Section and Overall Validity Scores as calculated using the EBL Critical Appraisal Checklist

tunities for all patients with cancer in accessing optimum care.
Many studies focused on females and certain cancer types predominantly [13, 14, 18, 19]. These study results are not generalisable. Future studies should discern the benefits in a population with different cancer types and socioeconomic status. No studies have been carried out on the benefits of or barriers to support group participation in Ireland.

4.2 Benefits of support groups participation

Lack of consistent use of the same validated questionnaires in the seven studies makes comparison and generalisability difficult. Only five of the seven articles have validity in all four categories. Thus, study quality must be considered when reaching conclusions from the results.
Two studies showed increased perceived benefits with increased attendance. This implies that encouraging patients to attend frequently is important to obtain greater benefits [20, 21]. Study strengths include a large sample size, weaknesses include cross-sectional design, therefore no causal relationship can be established, and confounders (recall and non-response bias). The studies were valid (overall validity of 82% and 77% respectively). Benefits from attendance varied on an individual basis, depending on coping mechanisms and support systems [13]. This is important as some people may benefit more than others (e.g. people lacking a support system may benefit more). These people should be particularly encouraged to attend. Strengths of this study include its longitudinal study design; thus, causation may be established. Weaknesses include selection bias and unreported drop-out rate. This study was not valid (overall validity: 66%).
Support group attendance was shown to have no impact on anxiety and depression in patients with cancer. Two studies used the HADS to measures anxiety and depression [18, 19]. The third used the CES-D to measure depression only [17]. The use of different instruments making comparisons between the studies more difficult. Weaknesses of these studies included variation between the two groups (study vs. control or peer-led vs. moderated) either initially or during long-term follow, loss to follow up and small sample size [17, 18]; affecting external validity. The studies using the HADS were both valid. The third study was not valid (overall validity: 73%). Despite these results, it is important to examine psychological well-being in a broader context than just anxiety and depression. It is well documented that psychological needs are common in people with cancer [8-10]. Anxiety and depression don't encompass all elements of psychological needs.
Osei et al conducted the first RCT to look at online support services in patients with prostate cancer [14]. It suggested the intervention may be helpful short term (<6 weeks), increasing patient's quality of life. Weaknesses of the study include a low response rate, lack of external validity (population not diverse and recruitment from a cancer registry only); resulting in selection bias. In addition, the inclusion criteria for age didn't match the population used. It is unclear if all questionnaires used were validated. Overall validity was 81%.
Results on the impact of support groups on health related quality of life were contradictory. A RCT showed that, health-related quality of life was positively associated with the support group attendance [19]. However, a descriptive cross-sectional study [23], shows no significant increase in health-related quality of life after attendance. As the first study is a RCT with a large sample size, its results were more convincing. Both studies were valid [19, 23].
A weakness of the studies was that many don't account for the use of other support resources by participants. This could be a confounding factor in terms of the benefits they receive from the support group. In addition, there is a lack of studies looking at long term effects of support group participation. These studies showed numerous benefits, but more studies must be done to investigate the quantitative benefits using the same validated instrument in different populations to attain external validity. These studies used populations with different cancer types, therefore the results cannot be easily compared.

4.3 Barriers/ Facilitators to support group participation

A lack of awareness regarding support groups exist [15, 21]. More must be done to educate patients and families about the services available. Practical barriers were addressed in both articles. They include scheduling conflicts and geographi-

cal location (may be addressed via online support groups).
Both studies found that encouragement from friends and family was a major facilitator of attendance. Education to ensure their support in the patients decision to attend support services is therefore important [21, 22].
Weaknesses of the studies included the lack of validated questionnaires, cross-sectional design meaning no causality could be established, recall bias not being controlled for and neither study being externally valid. Two studies were valid [21, 22], one was not [15].

4.4 Limitations

Only 10 articles were evaluated in this systematic review. Only one examined the long-term effect of support groups. Validity scores were not recalculated by another reviewer. Studies were predominantly non-randomised. Studies with primary focus on a certain ethnic/minority group and papers without full free text available were excluded, this may affect the generalisability of the results.

Conclusion

Evidence suggests that support services are an important and under-utilised resource, with various benefits for people with cancer. However, patients still encounter many barriers in accessing these services. Study weaknesses included a lack of clear selection criteria and external validity; which limited result generalisability. Different instruments, parameters, study types and populations were used to measure study outcomes. The development of a validated questionnaire would allow easier result comparisons. Three studies lacked total validity. Thus, while current research shows that support groups are beneficial, weaknesses in the studies have affected the quality of the evidence. RCT using validated questionnaires would provide quantitative data and better evidence. Further research could include looking at support service benefits or barriers in an Irish population and the psychological benefits of support services.

Acknowledgments

I would like to acknowledge my supervisor, Professor Seamus O'Reilly, consultant medical oncologist Cork University Hospital, for his help and guidance in the writing of this review. Additionally, all tables and figures were created using Microsoft Word 2017.

Table 2: Results Summary

Author (Date) / Title /Location	Objectives	Study type/ Methods	Sample size/ Study population/ Selection Criteria
Batenburg A. et al. (2014) [13] *''Emotional approach coping and the effects of online peer-led support group participation among patients with breast cancer: a longitudinal study''* The Netherlands	To investigate: The interaction between frequency of online support group participation and coping type and its impact on psychological well-being.	**Study type**: Longitudinal study **Method:** Study population completed questionnaires (t0, t1=6 months) assessing: • Participation levels. • Individual's emotional approach's to coping. • Psychological well-being.	**Sample size**: 133 **Study population:** Dutch patients with breast cancer using online support. **Inclusion Criteria:** • Website in Dutch • 24-hour discussion board • Active message board **Exclusion Criteria:** None given
Osei D.K. et al. (2013) [14] *'' Effects of an Online Support Group For Prostate Cancer Survivors: A Randomized Trial''* USA	To investigate: Whether use of an online support group increases the quality of life as perceived by patients with prostate cancer diagnosed in the past five years.	**Study type:** RCT **Methods:** • Population assigned randomly to intervention (online support) or control group (resource kits).	**Sample size:** 40 **Study population**: Men with prostate cancer diagnosed in last 5 year, aged 53-87 years. **Inclusion Criteria:** • Prostate cancer diagnosis within last 5 years • English literacy • Internet accessibility + email • Aged 40-85 years old • Married/living with partner **Exclusion Criteria:** • Prior participants of online support groups
Klemm P. (2012) [17] *''Effects of an online support group format (Moderated vs Peer-Led) on Depressive Symptoms and Extent of participation in women with breast cancer''* USA	To investigate if: Women with breast cancer will manifest less depressive symptoms if they participate in moderated online support groups versus peer-led support groups. Women with breast cancer participating in moderated online support groups will be more involved.	**Study type**: Randomised longitudinal study **Method:** Subjects randomised into 2 online support groups: • Moderated • Peer-led Intervention = 12 weeks Questionnaires: Demographics and outcome measures. Questionnaires completed: Before participation + at 6, 12 and 16 weeks.	**Sample size:** 50 **Study population:** Women with breast cancer, ≥21 years old, internet connection, English literacy, finished treatment within 32 months prior to participation. **Inclusion Criteria:** None given **Exclusion Criteria:** None given
Emilsson S. et al. (2012) [18] *''Support group participation during the post-operative radiotherapy period increases levels of coping resources among women with breast cancer''* Sweden	To investigate whether involvement in a support group while having post-operative radiotherapy impacts: Patients capacity to deal with stress and their cancer. Patients self-reported degree of anxiety and depression.	**Study type**: Non-RCT **Method:** Control group (n=33) Intervention group (n=34) Intervention = Support group participation (5 weeks) during post-operative radiotherapy Questionnaires used: • HADS • CRI Questionnaires given: • Before /Last week of /6 months after radiation therapy.	**Sample size**: 67 **Study population**: Women with breast cancer, attending the Department of Oncology at Umeå University Hospital for post-operative radiotherapy **Inclusion Criteria:** • Radiotherapy referral • Adult • Speak Swedish **Exclusion Criteria:** • Mental/physical disabilities
Björneklett H.G. (2012) [19] *'' Long-term follow-up of a randomized study of support group intervention in women with primary breast cancer''* Sweden	To investigate: The long-term impact of a support group intervention, in a RCT of women with primary breast cancer participating after cancer treatment.	**Study type:** RCT **Methods:** Participants randomised into intervention and controls. The intervention: 1 week of support group participation + 4-day follow-up after 2 months. Long-term follow up questionnaires: • European Organisation for Research and Treatment of Cancer • Quality of Life Questionnaire (EORTC QLQ-C30) • Breast Cancer Module questionnaire (BR 23) • HADS • Norwegian version of the FQ.	**Sample size:** 382 **Study population:** Women with primary breast cancer getting postoperative radiotherapy diagnosed 04/2002 - 11/2007 in Department of Oncology, Central Hospital, Västerås, Sweden. **Inclusion Criteria:** • Primary breast cancer just diagnosed • Physical/mental capability • Survival >12 months expected **Exclusion Criteria:** Individuals with: • Dementia • Serious visual/ auditory/ physically impairments • Severe mental illness • Active alcohol abuse • Prior attendance in group • Hx. malignant disease
Stevinson C. et al. (2011) [20] *'' Cancer support group participation in the United Kingdom: a national survey''* UK	To investigate: The features of support group members on a national scale Links between group and participant variables and outcomes perceived	**Study type:** Cross-sectional study **Method:** • - Postal survey of support groups in the UK. • Group leaders dispersed questionnaires to members. • Data collected on demographic and medical information, group attendance, perceived outcomes and psychosocial variables.	**Sample size:** 841 **Study population:** Cancer patients attending support groups in the UK **Inclusion Criteria:** None given **Exclusion Criteria:** None given

Author (Date) / Title /Location	Key findings	Strengths and Limitations
Batenburg A. et al. (2014) [13] *''Emotional approach coping and the effects of online peer-led support group participation among patients with breast cancer: a longitudinal study''* The Netherlands	***Effect of frequent use of support group:*** i.If approaching emotions less actively => Positive association with increased emotional well-being. i.If actively approaching emotions =>No change in well-being. ***Effect of infrequent use of support group:*** Coping style outweighed effects of online participation; i.If actively approaching emotions =>Increase in psychological well-being. ii. If approaching emotions less actively =>No change in emotional well-being.	**Strengths:** • Longitudinal study: can establish causal relationships. **Limitations:** • Emotional approach to coping, only measured at T0. • Only man in study removed: Results not generalisable to men (Selection bias). • Dropout rate unreported. • No exclusion criteria.
Osei D.K. et al. (2013) [14] *'' Effects of an Online Support Group For Prostate Cancer Survivors: A Randomized Trial''* USA	***Intervention group*** • Improvement in 3/6 statistically significant variables for QOL. • Scores back to baseline by week 8. ***Control Group*** • At 6 weeks, QOL had dropped for 6 of the QOL variables • Scores returned to baseline by week 8	**Strengths:** • First RCT looking at online support for patients with prostate cancer. **Limitations:** • Recruitment= Cancer registry: validity may be affected (external validity + if statistics not free from subjectivity). • Population isn't diverse (education level/ethnicity) + Low response rate: Hard to generalise results. • Long-term effect of intervention couldn't be determined. (8-week study). • Wasn't asked if control group used other resources: Confounding factor. • Inclusion criteria (Aged 40-85) don't match actual population used (Aged 53-87).
Klemm P. (2012) [17] *''Effects of an online support group format (Moderated vs Peer-Led) on Depressive Symptoms and Extent of participation in women with breast cancer''* USA	• Depressive symptoms did not vary significantly by time or group • Moderated group had increased participation in online support group	**Strengths:** • Randomisation **Limitations:** • No selection criteria defined. • More women with increased levels of depressive symptoms randomised to peer-led group. • 'Lurkers': more numerous in peer-led group. • Longitudinal study: Loss to follow (9 dropouts).
Emilsson S. et al. (2012) [18] *''Support group participation during the post-operative radiotherapy period increases levels of coping resources among women with breast cancer''* Sweden	***CRI questionnaire:*** • Study group participants improved coping resources due to intervention. ***HADS questionnaire:*** • No significant variation between the study and control group.	**Strengths:** • Clear selection criteria defined. • All participants received radiotherapy at same hospital- variability minimised. • Non RCT provides a higher level of evidence for causality than observational studies. **Limitations:** • Significant variation found during initial analysis (study vs. control group). • Findings not generalisable + Randomisation not possible: small sample size.
Björneklett H.G. (2012) [19] *'' Long-term follow-up of a randomized study of support group intervention in women with primary breast cancer''* Sweden	i.Significant impact on the following after intervention: • 3 elements in EORTC-QLQ30 and BR 23 **and** • Fatigue (Norwegian version of the FQ) ii. No significant impact on levels of anxiety and depression (HADS).	**Strengths:** • RCT is second only to a systematic review in the hierarchy of evidence. • Relatively large sample size. • Selection criteria clearly defined. • Population was homogenous (women with primary breast ca.). • Long-term follow-up (average 6.5 years) with good response rate. **Limitations:** • During long-term follow-up drop out was marginally higher in the control group: Long-term comparisons between the 2 groups harder. • Participants included in study without prior screening for possible needs: Some may have needed rehabilitation more than others.
Stevinson C. et al. (2011) [20] *'' Cancer support group participation in the United Kingdom: a national survey''* UK	***Socio-demographic:*** • Overrepresented = white (96.8%) female (68.2%). • More participation from men/ those with lower education/ socioeconomic status than in previous studies. ***Perceived benefit:*** • Positive psychological outcomes perceived in women > men. • Frequent meeting attendance (>75%) positively associated with higher reports of benefits.	**Strengths:** • Large sample size. • Nationwide survey. • No loss to follow-up: Cross-sectional study. **Limitations:** • Cross-sectional study: causal relationships cannot be made. • Non-response bias. • No selection criteria defined.

Table 2: Results Summary

Sherman A.C. et al. (2008) [21] *'' Determinants of Participation in Cancer Support Groups: The Role of Health Beliefs ''* USA	To investigate: Group attendance and its associations for patients with varied malignancies getting treatment at a big academic oncology centre	**Study type:** Cross-sectional study **Methods:** • Recruitment: During routine clinic visits • Survey used: created based on the Health Belief Model and literature.	**Sample size:** 425 **Study population:** Outpatients with varied disease sites getting treatment at Winthrop P. Rockefeller Cancer Institute at University of Arkansas for Medical Sciences **Inclusion Criteria:** None given **Exclusion Criteria:** • Time since diagnosis (>4 months) • Inadequate English literacy. • Serious cognitive impairment.
Ussher J.M. et al. (2008) [15] *''A Qualitative Analysis of Reasons for Leaving, or Not Attending, a Cancer Support Group''* Australia	To investigate: Factors that influencing leaving and non-attendance in cancer support groups	**Study type:** Longitudinal, Cross-sectional and qualitative study. **Methods:** • Drop-Outs: Follow-up (12 months): Questionnaire on experience of support group participation. • 87 Drop-outs completed questionnaires with reasons they left. ***Non-Attendees:*** Recruitment: clinics waiting rooms in hospitals. Participants completed: i.Demographic questionnaire ii.Individual or focus group interview.	**Sample size:** 347 in longitudinal study of Drop-Outs + 26 in Cross-sectional study of Non-Attendees **Study population:** • Drop-outs from 47 cancer support groups over 12 months. • Non-Attendees: Patients from 4 oncologists in 3 Sydney hospitals **Inclusion Criteria:** None given **Exclusion Criteria:** None given
Grande G.E. et al. (2006) [22] *''How do patients who participate in cancer support groups differ from* those who do not'' UK	To investigate: The variations between patients with cancer attending community support groups and a random sample of non-attenders on the Cancer Registry	**Study type:** Cross-Sectional Study **Methods:** • Recruitment of support group attendees: Cambridge Cancer Help Centre, community support group for people with cancer. • Comparison sample recruitment: by East Anglian Cancer Intelligence from Cancer Registry records: 200 non-attendees random selection. • Data collected via Cancer Registry records, self-completed and postal surveys.	**Sample size:** 107 (63 participants + 44 non-participants) **Study population:** Not specified. **Inclusion Criteria:** • ≥ 18 years old • Malignant neoplasm diagnosis 1990 - 2002 • No recorded date of death, and residence inside the catchment area of the CCHC. **Exclusion Criteria:** • CCHC members • Patients with no recorded GP
Michalec B. (2005) [23] *''Exploring the Multidimensional Benefits of Breast Cancer Support Groups''* *USA*	To investigate: Variations in breast cancer survivors' quality of life after attendance in a breast cancer support group. If all participants in breast the cancer support groups are uniformly benefiting	**Study type:** Qualitative, Cross-sectional study **Methods:** Data collection: • Telephone interviews • Individual participant-level survey data was joined with tumour registry data (e.g. age and stage at diagnosis)	**Sample size:** 958 **Study population:** Breast cancer survivors on the Eastern North Carolina Tumour Registry. **Inclusion Criteria:** None given **Exclusion Criteria:** None given

Sherman A.C. et al. (2008) [21] *'' Determinants of Participation in Cancer Support Groups: The Role of Health Beliefs ''* USA	***Sociodemographics:*** • Attendance > for Caucasian patients. • Education > in participants than nonparticipants. • Participation > in those with breast cancer or multiple myeloma. **Benefits to attendance:** • Perceived benefits: positively associated with increased group attendance. **Barriers to attendance:** • Geographical barriers (OR = 2.74; CI = 1.09–6.93) • Awareness of support group existence **Facilitators to attendance:** • Increased stress from illness/ disease severity (OR= 4.07; CI= 1.42–11.60) • Encouragement by family or friends (OR= 5.04; CI= 1.98–12.81)	**Strengths:** • Relatively large sample size. • Proportional sampling based on disease site. • Inclusion of patients at different stages of treatment. **Limitations:** • No inclusion criteria defined. • Cross-sectional study: causal links between health beliefs and group participation cannot be established. • Recall bias not controlled for. • Questionnaire not validated. • Results not generalisable to cancer centres in other regions (In sample-gynaecological cancers: underrepresented, haematological cancers: overrepresented).
Ussher J.M. et al. (2008) [15] *''A Qualitative Analysis of Reasons for Leaving, or Not Attending, a Cancer Support Group''* Australia	***Reason for Drop-outs*** Two main reactions: i.Positive outlook on support group: Reasons to leave including practical issues and "time to move on" ii.Negative outlook on support group: Reasons to leave was dissatisfaction (e.g. problem with group leader / organisation). ***Reasons for Not Attending*** i.Individual factors: Avoiding being labelled a "cancer patient," personality issues, and sufficient support already. ii. Group factors: Lack of awareness about groups, practical issues, association of groups with negativity, didn't find a good group.	**Strengths:** • Relatively large sample size for finding the dropouts. • Inclusion of drop outs as well as non-attendees: similar/different reasons for non-attendance elicited. • Longitudinal study design to look at dropouts. **Limitations:** • No selection criteria defined. • Small sample size for the non-attendees + only recruited from hospital clinics (selection bias).
Grande G.E. et al. (2006) [22] *''How do patients who participate in cancer support groups differ from* those who do not'' UK	**Results:** • Support group members: > proportion of younger, educated, female and > users of formal support than control group. • Multivariate analysis determined that independent predictors of group attendance were: i.Views on support group benefits ii.Supportiveness of significant people in terms of attendance ii.Active coping response v.Lack of support system (from a ''special person'')	**Strengths:** • Relatively large sample size. • Selection criteria clearly defined. **Limitations:** • Cross-sectional study: causality cannot be established. • Attendees judged the benefits of support group attendance based on experience, non-attendees judged based on what they thought benefits would be: difficult comparison. • Low response rate in comparison group (28%).
Michalec B. (2005) [23] *''Exploring the Multidimensional Benefits of Breast Cancer Support Groups''* *USA*	**Results:** • Current/past attendance positively associated with increased quality of life versus non- attenders. Association insignificant after controlling for confounding factors. • Attendees vs non-participants, attendees were: i.Younger i.Better income/education levels i.More likely employed and married	**Strengths:** • Regional data used: Decreases selection bias. • Diverse regional population (race, income, place of residence, and education level). • Looks at cancer survivors who have attended any type of breast cancer support groups versus just focusing on a specific support groups type. • Confounding factors accounted for. Limitations: • No selection criteria defined. • Cross-sectional study: causal relationships cannot be derived.

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