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Review

Improving subjective perception of personal cancer risk: systematic review and meta-analysis of educational interventions for people with cancer or at high risk of cancer

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Abstract

***Background*: Newly diagnosed patients with cancer require education about the disease, the available treatments and potential consequences of treatment. Greater understanding of cancer risk has been found to be associated with greater health-related quality of life, improved psychological adjustment and greater health-related behaviours. The aim of this sytematic review was to assess the effectiveness of educational interventions in improving subjective cancer risk perception and to appraise the quality of the studies.**

***Methods*: We conducted a systematic review and meta-analysis of randomised controlled trials (RCTs) and prospective observational studies. Eligible studies were identified via Medline, PsycINFO, AMED, CINAHL and Embase databases. After screening titles and abstracts, two reviewers independently assessed the eligibility of 206 full-text articles.**

***Results*: Forty papers were included in the review; the majority of studies were conducted among breast cancer patients ($n = 29$) and evaluated the effect of genetic counselling on personal perceived risk ($n = 25$). Pooled results from RCTs ($n = 12$) showed that, both in the short and long term, educational interventions did not significantly influence risk perception level (standardised mean difference 0.05, 95% CI −0.24–0.34; $p = 0.74$) or accuracy (odds ratio = 1.96, 95% CI: 0.61–6.25; $p = 0.26$). Only one RCT reported a short-term difference in risk ratings ($p = 0.01$). Of prospective observational studies ($n = 28$), many did demonstrate changes in the level of perceived risk and improved risk accuracy and risk ratings in both the short and long term. However, only one (of three) observational studies reported a short-term difference in risk ratings ($p < = 0.003$).**

***Conclusion*: Further development and investigation of educational interventions using good quality, RCTs are warranted.**

Introduction

People newly diagnosed with cancer require education about the disease, available treatments and the potential consequences of treatment. A review by Mills and Sullivan [1] found that effective cancer education increased patients' control and involvement in their care, reduced psychological distress and improved adherence to treatment. Perception of cancer risk has been found to be theoretically and empirically relevant in motivating cancer screening and risk reduction behaviours [2–4]. Research by Kreuter [5,6] concluded that people who underestimate their risk of developing cancer may be less likely to engage in health-protective behaviours, whereas those who overestimate their risk may worry excessively, overdo protective behaviours and burden the health care system. Cancer risk perception is associated with health-related quality of life, including psychological adjustment and health behaviours [7]. For example, Waters *et al*. [8] found that high perceived cancer risk was associated with lower mental and physical health-related quality of life. Kinsinger *et al*. [9] observed that perceived risk of breast cancer was positively associated with depression, anxiety and worry about cancer.

Despite the established importance of risk perception and the increasing number of educational interventions targeting risk perception for both cancer patients and people at risk of cancer, there is little research investigating the efficacy of these interventions. In 2006, a systematic review by Braithwaite and colleagues [10] examined the impact of genetic counselling for breast, ovarian and colorectal cancers on a range of cognitive, affective and behavioural outcomes. On the basis of evidence from controlled trials, the review concluded that genetic counselling does not influence risk perception; however, other evidence from prospective studies did suggest an increase in the accuracy of perceived risk over time. More recently, Albada *et al*.

conducted a review that specifically focused on the effects of tailored information about cancer risk and screening interventions [11]. This review found that compared with standard information, tailored information using behavioural constructs and risk factors improved the level of cancer risk perception.

No reviews have investigated the impact of all types of educational interventions on cancer risk perception. The aim of this systematic review and meta-analysis was to (1) assess the effectiveness of educational interventions on subjective cancer risk perception in the short and long term, across all types of interventions and cancers, and (2) critically appraise the quality of the included studies.

Methods

The protocol for this review was registered in the PROSPERO register (Registration number: CRD42012002861) http://www.crd.york.ac.uk/PROSPERO in August 2012. The preferred reporting items for systematic reviews and meta-analyses statement guidelines [12] were followed to identify and screen publications, extract data and describe the systematic review protocol.

Inclusion criteria

Studies published in a peer-reviewed journal that met all of the following criteria were included in the review:

- The study evaluated the impact of an educational intervention on cancer risk perception.
- The intervention was an educational intervention of any form including genetic counselling.
- The study assessed and reported personal cancer risk perception as a primary or secondary outcome.
- The intervention targeted people affected by cancer (cancer patients and cancer survivors), people who were at high or moderate risk of developing cancer, or who were referred to genetic counselling because of a personal or family history of cancer.

Exclusion criteria

We excluded studies that

- involved only caregivers;
- were conducted only among the general population (i.e. not targeted at risk groups); and
- were case studies, conference abstracts, systematic reviews or meta-analyses.

Search strategy

In January 2013, we searched international electronic bibliographic databases Medline (from 1950 to January 2013), PsycINFO (from 1806 to January 2013), Allied and Complementary Medicine (from1985 to January 2013), Cumulative Index to Nursing and Allied Health Literature (from 1982 to January 2013) and Embase (from 1966 to January 2013). We also conducted hand searches of the reference lists of included papers. With the exception of human research, the search was conducted without limitations by country, language or year. Our search strategy was developed in Medline and adapted to other databases (Appendix A). In addition, to examine how well melanoma was captured under the broader term of 'neoplasm', we conducted a complementary search using 'melanoma' as a Medical Subject Headings (MeSH) term and a text word. This was performed to facilitate future work in our broader melanoma research programme.

Study selection

Study selection was conducted in two distinct rounds. In the first round, one reviewer (MD) screened all titles and abstracts for non-research articles, duplicates and ineligible publications such as single case reports, letters, commentaries, conference abstracts or those focused on other topics. Non-English abstracts were translated using Google Translator (http://translate.google.com.au/). In the second round, the full text of all remaining papers was examined independently by two reviewers (MD and CW). When there was disagreement, two external reviewers (NK and AC) were consulted, and inclusion was agreed by consensus.

Data were extracted using a predefined data form developed using the participants, interventions, comparators, outcomes and study (PICOS) design approach [12].

Appraisal and quality assessment

A specific quality appraisal tool was used for each type of study design (prospective observational or randomised controlled trial (RCT)). Methodological quality was assessed independently by two reviewers (MD and CW). For RCTs, we used the Cochrane collaboration tool for assessing the risk of bias [13]. It is a domain-based evaluation, which is used to critically assess six domains of bias: selection bias, performance bias, detection bias, attrition bias, reporting bias and other bias [13]. For assessing the quality of prospective observational studies, we used the Quality Assessment Tool for Quantitative Studies [14], which has been judged to be suitable to use for systematic reviews of effectiveness [15]. This tool includes 21 items separated into eight components: selection bias, study design, confounders, blinding, data collection methods, withdrawals and dropouts, intervention integrity and analysis.

Analysis of the effectiveness of the educational interventions

Synthesising the results of all the included studies was challenging because of the heterogeneity of study designs, populations, interventions and outcomes in the included studies. We synthesised the evidence according to how risk

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perception was reported in each paper (mean perceived risk, risk accuracy, and risk rating), as it was assessed using different scales and presented in different ways across studies. We presented results separately for RCTs and prospective observational studies. Results for both study types were presented as forest plots where possible; however, a formal meta-analysis of results (i.e. to show a pooled effect) was performed only for RCTs because of the heterogeneous prospective observational study designs. We used Cochrane software RevMan5 (The Cochrane Collaboration, Copenhagen: The Nordic Cochrane Centre, 2012) [16] to summarise the estimates of effect and to produce figures.

Results

Literature search

We identified 3386 papers through database searching, and 13 additional papers were located through manual searching (Appendix B). These were reduced to 206 potentially eligible studies after removing duplicates and applying the inclusion and exclusion criteria to the titles and abstracts. After the assessment of the full text of the remaining papers, we included 40 studies that examined the effect of educational interventions on cancer risk perception among people affected by cancer, or at moderate or high risk of cancer, or who were referred to genetic counselling because of a personal or family history of cancer. Of these, 12 were RCTs and 28 were prospective observational studies, conducted in the USA ($n = 11$), UK ($n = 13$), Sweden ($n = 4$), Australia ($n = 3$), Canada ($n = 3$), the Netherlands ($n = 2$), Norway ($n = 1$), Spain ($n = 1$), Israel ($n = 1$) and Denmark ($n = 1$).

Characteristics of included studies

Randomised controlled trials ($n = 12$)

Ten RCTs were conducted among breast cancer patients and two among melanoma patients (Table 1). Sample sizes ranged from 40 to 545 participants, and the mean number of participants was 248. Of the 10 breast cancer RCTs, four tested the effect of genetic counselling or genetic risk assessment, [17–20] one tested the effect of a pre-visit (breast cancer genetic counselling visit) educational website versus usual care [21] one measured the effect of an alternative model of cancer genetics consultation by genetic nurse specialists versus standard service [22], one evaluated the effect of a computer-based programme followed by genetic counselling versus standard one-on-one genetic counselling [23], one evaluated the impact of a psycho-educational information pack versus scientific information pack versus standard care [24], one evaluated the effect of a psycho-educational group intervention [25] and one tested the effect of genetic counselling plus nurse consultation versus standard genetic counselling [26]. Of the two interventions in melanoma education, one evaluated an intervention with interactive education, education brochure and telecommunication reminders to perform skin self-examination versus usual care [27], and one evaluated the effect of a multimedia health education programme (Skinsafe) [28].

Prospective observational studies ($n = 28$)

Of the 28 prospective observational studies, 25 used a standard 'pre and post' design [29–54] whereby all individuals were assessed before and after participation in the intervention, and three studies [43,55,56] used a different 'pre and post' design whereby two groups were given the intervention at different times and the two groups were compared at the completion of the study. The majority ($n = 18$) of the observational studies was conducted among breast cancer patients, two among colorectal cancer patients, one with ovarian cancer patients, one among pancreatic cancer patients and six with familial cancer patients (Table 1). Sample sizes ranged from 34 to 517 participants, and the mean number of participants was 152. Most ($n = 19$) evaluated the effect of genetic counselling on personal perceived risk [29,32,33,35–38,40,42–45,47–50,52,53,55], three evaluated the effectiveness of cancer education sessions [39,51,54], one involved a cancer risk evaluation programme [34], one was an educational support group [46], one was a cancer genetics consultation [31], one was an educational video intervention [56], one was a cancer counselling and screening programme [30] and one was an information aid [41].

Risk perception measures

A range of self-reported measures of perceived risk were used across studies, including categorical and continuous variables, and both absolute and comparative risk estimates. Perceived risk was measured using scales of various length, ranging from one to five items; 17 studies (41%) [17,21,22,24,28,30,31,34,36,43,45,47,50–53,56] used a single-item measure of risk perception, eight used a two-item measure [18,19,26,32,39,40,49,54], six used a three-item measure [23,33,35,37,46,48], two used a four-item measure [20,42], two studies used a five-item measure [29,55], and five studies did not describe the measure used to assess risk perception [25,27,38,41,44].

Impact of cancer educational interventions on risk perception

Level of perceived risk

Six RCTs reported the impact of educational interventions on the level of risk perception; four of these were able to be summarised as the standardised mean difference between treatment group means, standardised by the standard deviation at follow-up pooled across treatment groups (Figure 1). Three of the studies reported short-term ($<= 3$ months) effects. The pooled result indicated no short-term effect of these interventions (standardised

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Table 1. Characteristics of included studies

Reference	Country/ region	Type of cancer	Type of intervention	Participants	N (Baseline)
Randomised controlled trials					
Albada 2012 [21]	the Netherlands	Breast	Pre-visit educational website (E-info gene) versus usual care (brief standard pre-visit leaflet)	Women attending a genetic counselling clinic for breast cancer	197
Appleton [24]	UK	Breast	Psycho-educational (scientific and psychosocial information) written information pack versus scientific information pack versus standard care	Women attending the Ardmillan Familial Breast Cancer Clinic	163
Aneja 2012 [27]	USA	Melanoma	Intervention with interactive education and telecommunication reminders versus usual care	Participants from dermatology clinics with low or high risk of melanoma	210
Bowen 2004 [20]	USA	Breast	Individual genetic counselling versus group psychosocial counselling versus delayed intervention	Participants were recruited from among family members of women with breast cancer.	348
Brain 2000 [18]	UK	Breast	Multidisciplinary genetic assessment versus surgical assessment	Women residing in Wales from two family cancer clinics	545
Braithwaite 2005 [19]	UK	Breast	GRACE (genetic risk assessment in the clinical environment) tool versus genetic risk counselling	Women with a family history of breast cancer	72
Fry 2003 [22]	UK	Breast	Novel community-based service versus standard regional service	Women referred to the regional clinical genetics department for breast cancer genetic risk counselling	373
Glazebrook 2006 [28]	UK	Melanoma	Multimedia health education programme (Skinsafe) versus control	Patients at high risk of developing melanoma and attending family practices within Nottinghamshire	459
Green 2004 [23]	USA	Breast	Computer-based programme followed by genetic counselling versus standard one-on-one genetic counselling	Women with personal or family histories of breast cancer recruited from outpatient clinics	211
Kash 1995 [25]	USA	Breast	Psycho-educational group intervention versus control	Women at high risk of breast cancer	40
Lerman 1995 [17]	USA	Breast	Breast cancer risk counselling versus general health counselling	Women with family history of breast cancer identified by a relative who was under treatment for breast cancer at a comprehensive cancer centre	200
Roshanai 2009 [26]	Sweden	Breast	Standard genetic counselling + nurse consultation versus standard genetic counselling alone	Women attending the cancer genetic clinic of Uppsala University Hospital	163
Observational studies					
Alexander 1995 [54]	USA	Breast	90-min breast cancer educational session with general internist	Women at high risk of breast cancer who participated in the tamoxifen breast cancer prevention trial	59
Bish 2002 [40]	UK	Breast/ovarian	Genetic counselling	Women who have been treated for breast or ovarian cancer and unaffected women referred to the Department of Clinical Genetics for genetic counselling	181
Bjorvatn 2007 [35]	Norway	Breast/ovarian	Genetic counselling	People receiving counselling for cancer risk at the genetic outpatient clinics of in three university hospitals in Norway	213
Cabrera 2010 [53]	Spain	Breast	Genetic counselling	Participants with familial history of breast cancer who were referred for genetic counselling at a hospital in Barcelona	212
Codori 2005 [52]	USA	Colorectal	Genetic counselling	Adults at increased risk of HNPCC due to a family history of colorectal cancer.	101
Collins 2000 [51]	Australia	Colorectal	1-h session at a family cancer clinic + follow-up letters outlining the issues discussed in the session	Individuals referred to a family cancer clinic by their GPs, family members or self referred	126
Cull 1998 [56]	UK	Breast	Educational video before clinic consultation	Women newly referred to a breast cancer family clinic	128

(Continues)

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Table 1. (Continued)

Reference	Country/ region	Type of cancer	Type of intervention	Participants	N (Baseline)
Evans 1994 [55]	UK	Breast	Genetic counselling + population risk information	Women who were referred to a genetic clinic for counselling	517
Gagnon 1996 [39]	Canada	Breast	Special surveillance breast programme (20-min session with a breast surgeon)	Women who made an appointment at the Memorial Sloan Kettering cancer centre special surveillance breast programme (a programme for women at high risk of breast cancer)	94
Gurmankin 2005 [34]	USA	Breast	Cancer risk evaluation programme including genetic counselling and testing	New patients visiting the University of Pennsylvania's breast and ovarian cancer risk evaluation programme	108
Hopwood 1998 [38]	UK	Breast	Genetic counselling	Women with twofold or greater risk than the population referred to the family history clinic for the first time by their GP or hospital clinician	158
Hopwood 2003 [33]	UK	Breast	Genetic counselling	Women with calculated lifetime breast cancer risk to age 80 years of 1 in 6, attending the Family History Clinic in South Manchester	158
Hopwood 2004 [50]	UK	Familial cancers: breast 75%, bowel 17%, ovary 9% and other 2%	Genetic counselling	Individuals attending cancer genetic risk counselling for the first time	162
Kelly 2005 [49]	USA	Breast	Genetic counselling + testing + face to face meeting for test result disclosure	Women of Ashkenazi Jewish descent with a family history or personal history of breast cancer	99
Kelly 2008 [48]	USA	Ovarian	Genetic counselling + testing + face to face meeting for test result disclosure	Women of Ashkenazi Jewish descent with a family history or personal history of ovarian cancer	78
Kent 2000 [47]	UK	Breast	Genetic counselling	Asymptomatic women referred by their GP to the Northern General Hospital Breast Cancer Family History Clinic Sheffield	69
Landsbergen 2010 [46]	the Netherlands	Breast	Educational support group	Women with a BRCA mutation	34
Liden 2003 [32]	Sweden	Breast, ovarian and colorectal	Genetic counselling	Individuals referred by their GP or oncologist who are attending genetic counselling at the oncogenetic outpatient clinic at the University hospital, Uppsala	77
Lobb 2004 [31]	Australia	Breast	Breast cancer genetics consultation	Women from families at high risk breast cancer attending their first consultation at a familial cancer clinic within Australia before genetic testing	158
Maheu 2010 [30]	Canada	Pancreatic	Pancreatic cancer counselling and screening programme	Individuals with a family history of pancreatic cancer participating in counselling, and individuals with a BRCA2 mutation participating in a screening programme	198
Meiser 2001 [45]	Australia	Breast	Genetic counselling	Women with a family history of breast cancer who approached familial cancer clinics in five Australian states between November 1996 and January 1999	218
Mertens 2008 [44]	USA	Breast	Oncologist-based counselling	Patients referred for assessment of breast cancer risk at a high risk clinic of a comprehensive breast cancer	81
Mikkelsen 2007 [43]	Denmark	Breast	Genetic counselling		213

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Table 1. (Continued)

Reference	Country/ region	Type of cancer	Type of intervention	Participants	N (Baseline)
				Women at risk of breast cancer referred for genetic counselling by their physician	
Nordin 2002 [36]	Sweden	Breast, ovarian, and colorectal	Genetic counselling	Subjects referred for genetic counselling regarding risk of breast, ovarian or colorectal cancer at the oncogenetic outpatient clinic at Uppsala University Hospital	63
Rantala 2009 [29]	Sweden	Breast, ovarian, colorectal, endometrial and gastric	Genetic counselling	Patients referred to oncogenetic counselling for breast, ovarian, colorectal, endometrial and gastric cancer at the Karolinska University Hospital	215
Sagi 1998 [42]	Israel	Breast	Genetic counselling	Women attending a genetic clinic because they have a family history of breast cancer	60
Warner 2003 [41]	Canada	Breast	Breast cancer information aid (booklet and audiotape)	Women with a family history of breast cancer	203
Watson [37]	UK	Breast	Genetic counselling	Women with a family history of breast cancer attending a cancer genetics clinic for counselling	268

BRCA, breast -ovarian cancer susceptibility gene; HNPCC, hereditary nonpolyposis colorectal cancer.

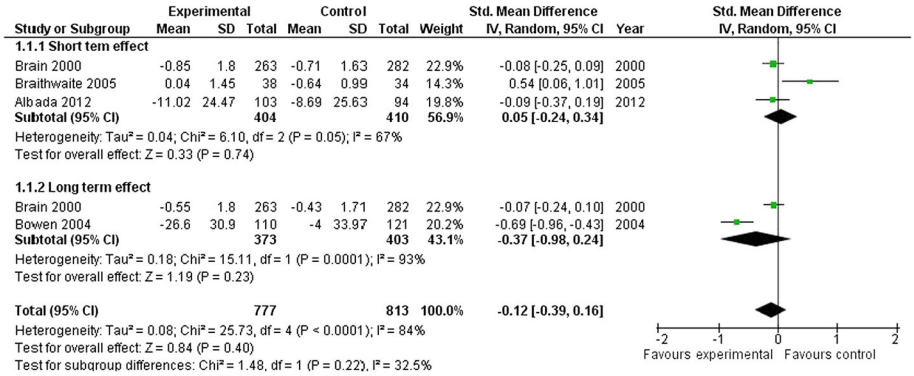

Figure 1. Forest plot of the effect of educational interventions on mean perceived risk in randomised controlled trials in the short and long term. We stratified according to the length of follow-up, defined as short term (≤3 months) or long term (>3 months). Effectiveness was defined by the standardised mean difference between treatment group means, standardised by the standard deviation at follow-up pooled across treatment groups. A positive difference indicates increased mean risk perception in the intervention group relative to the comparison group. Perceived risk could increase or decrease, but the measure of effect is whether the education intervention changed risk perception. Standardised differences are pooled using random effects chosen because of differences between the trials in interventions and scales

mean difference 0.05 (95% CI −0.24, 0.34); $p = 0.74$). Two trials reported long-term effects (>3 months); one after 6 months follow-up [20] and one after 9 months follow-up [18] (Figure 1). The pooled long-term effect was small (standardised mean difference −0.37; (95% CI −0.98, 0.24) and not statistically significant ($p = 0.23$). There was significant heterogeneity of effect sizes between studies ($\chi^2 = 25.73$; df = 4; $N = 5$; $p < 0.0001$); however, it was difficult to explore sources of heterogeneity because of the small total sample.

Two RCTs [23,25] that measured the mean level of risk perception were not included in Figure 1; the study by Green and colleagues [25] did not report a standard deviation, and the study by Kash *et al.* [25] reported a risk perception score range. Green's study [23] found that high risk participants' perception of risk of developing breast cancer decreased significantly from 62 to 56 (on a scale of 0–100) ($p = 0.006$) after either counselling or computer programme use. Kash's study [25] also concluded that the psycho-educational intervention significantly reduced perceived risk (mean perceived score decreased from 51–60% at baseline to 21–30% at 6 weeks, 6 months and 1 year; $p < 0.01$), which had been highly overestimated by women prior to intervention use. There was not enough information available to include the study by Appleton *et al.* [24] in Figure 1. However, they found that people who received the scientific information only experienced a significant decrease in perceived likelihood of developing breast cancer ($p = 0.039$).

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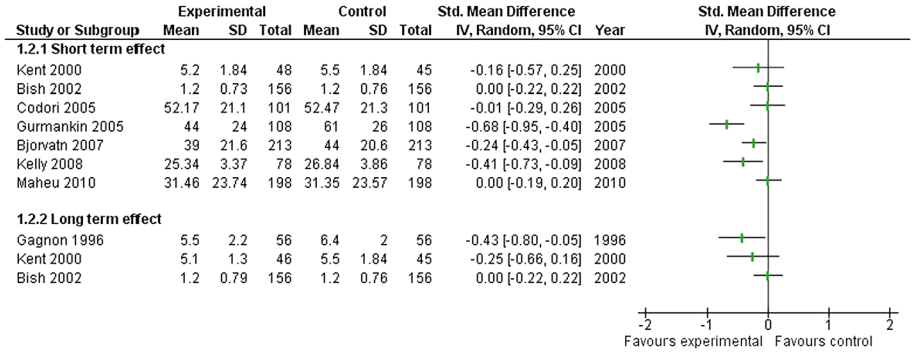

Figure 2. Forest plot of the effect of educational interventions on perceived risk in observational studies in the short and long term. We stratified according to the length of follow-up, defined as short term (≤3 months) or long term (>3 months). Effectiveness was defined by the standardised mean difference, between baseline and post-clinic means, standardised by the standard deviation at follow-up pooled across groups. A positive difference indicates an increased mean perceived risk post-intervention relative to baseline. Because of heterogeneous study designs, pooled effects are not presented

Figure 2 summarises the impact of the interventions on mean level of risk perception from eight prospective observational studies. Of seven studies assessing short-term outcomes, three reported a statistically significant change from baseline level of mean perceived risk [34,35,48], and four studies [30,40,47,52] reported no statistically significant change. Over the longer term, one study reported a statistically significant change from baseline level of mean perceived risk [39], and two studies [40,47] reported no change.

Another three studies [29,42,44] did not report standard deviations and thus could not be presented in Figure 2; however, each of these studies showed improvements in perceived risk after genetic counselling. Mertens and colleague's [44] found that patient's 5-year risk perceptions decreased significantly (-11.5%; $p < 0.0001$) but remained significantly higher than the objective estimates (mean difference 18.7%; $p < 0.0001$). Rantala and colleague's study [29] reported a statistically significant decrease in perceived risk reported by unaffected subjects after genetic counselling ($p < 0.001$). Sagi *et al.* [42] also found a significant decrease in perceived risk after genetic counselling ($t = 2.2$, df = 45, $p \leq 0.05$).

Risk accuracy

Risk accuracy was described as the level of concordance between perceived risk estimates and calculated or counselled risk estimates (objective risk). However, different epidemiological models of risk and definitions of accuracy were used across studies.

Two RCTs [17,26] assessed the association between educational interventions and risk accuracy (Figure 3).

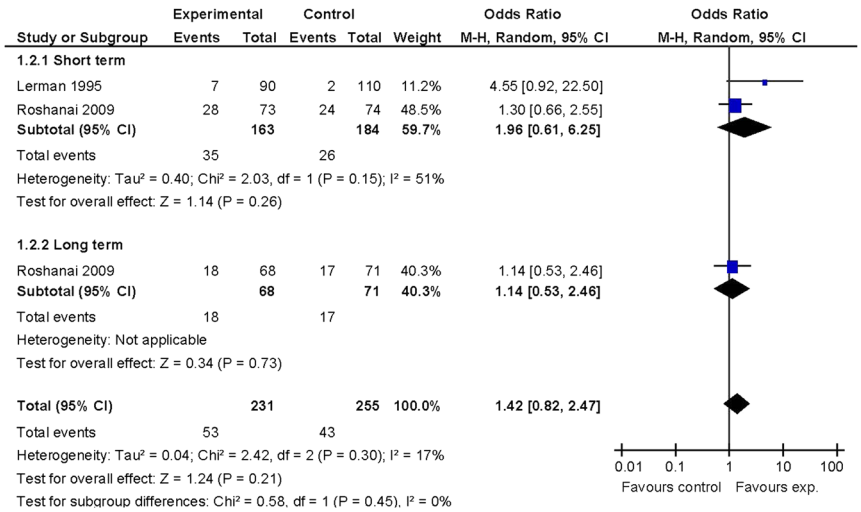

Figure 3. Forest plot of the effect of educational interventions in randomised controlled trials on risk accuracy in the short and long term. We stratified according to the length of follow-up, defined as short term (≤3 months) or long term (>3 months). Effectiveness was defined by the difference in risk accuracy (%), between groups. An odds ratio of greater than 1 indicated an increased accuracy in risk perception. Standardised differences were pooled using random effects

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The pooled results show that in the short term, there was no difference in risk accuracy for the intervention versus comparison group (odds ratio (OR) for improved risk accuracy = 1.96; 95% CI: 0.61, 6.25; $p = 0.26$). Only one randomised trial [26] reported the long-term (8 months) effect of the intervention and found no difference (OR = 1.14; 95% CI: 0.53, 2.46; $p = 0.73$).

Improvements in accuracy of risk perception were observed in eight of 10 observational studies that evaluated short-term effectiveness (Figure 4), and most of these demonstrated strong effects; for example, four studies [32,33,36,38] had an OR > 4 for improved risk accuracy. In the long term, four studies [33,37,43,55] reported significant improvements in risk accuracy after educational intervention (Figure 4).

One prospective cohort study by Alexander *et al.* [54] reported subjective and objective perceived risks as median risk estimates. This study found that initially, women substantially overestimated their chance of getting breast cancer; however, after an educational intervention, perceived risk shifted closer to the calculated objective risk although remained significantly higher ($p < 0.0001$).

Risk rating

Six studies (three RCTs [22,27,28] and three observational [41,49,51]) reported the proportion of participants who *believed* their risk to be moderate or high compared with the proportion whose *objective* risk was moderate or high (Table S1). Most of these studies demonstrated that at baseline, the majority of participants overestimated their risk as moderate or high compared with their objectively calculated risk. In the short term, one RCT [22] and one observational study [41] reported a statistically significant difference in risk ratings ($p = 0.01$; and $p <= 0.003$, respectively). Two other studies [28,49] did not report objective risk to compare with participants' subjective risk.

Predictors of change in perceived risk

Two RCTs and eight observational studies used multiple regression to identify the predictors of improvement in risk perception; Table S2 shows the statistically significant predictors that were identified. Covariates found to be associated with a change in perceived risk included baseline risk perception, age, ethnicity and cancer-related worry, among several others. One RCT [21] and one observational study [45], not presented in the table, found that none of the tested covariates (age, baseline genetic knowledge, and educational level) were significantly associated with change. Baseline perceived risk was the most strongly and consistently reported factor associated with post-intervention risk perceptions across studies.

Quality assessment

The quality assessment of included RCTs showed that for items related to potential risk of bias due to allocation, nine [17,18,20–24,27,28] of 12 RCTs provided a description indicating that the sequence was adequately generated and that the allocation was adequately concealed, and three studies [19,25,26] had unclear descriptions of these processes. Blinding of participants, personnel and outcome assessors was reported as present in five studies [17–19,25,26], not adequately described in three [20,22,23], and four explicitly described their study was not blinded [21,24,27,28].

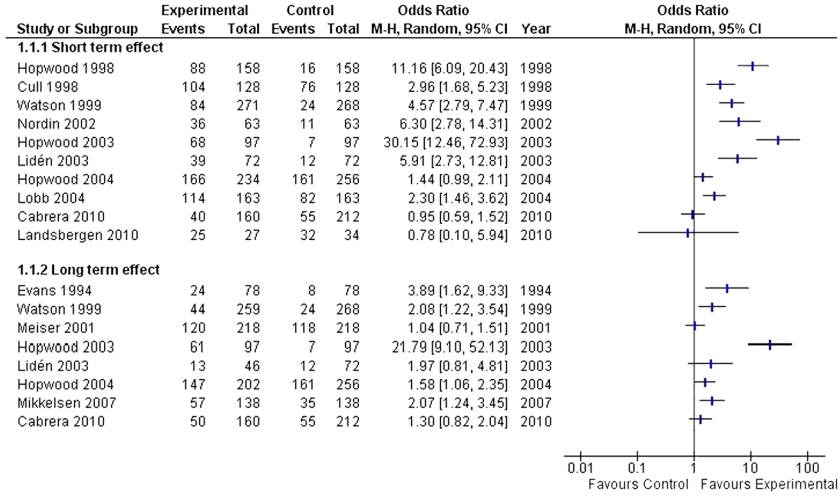

Figure 4. Forest plot of the effect of educational interventions on risk accuracy in observational studies in the short and long term. Results are stratified according to the length of follow-up, defined as short term ≤ 3 months or long term >3 months. Effectiveness is defined by the difference between baseline and post-intervention risk accuracy (%). An odds ratio of greater than 1 indicates increased accuracy in risk perception. Because of heterogeneous study designs, we did not present the pooled effects

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Incomplete outcome data were adequately described in two studies [21,24], unclearly described in nine studies [17,19,20,22,23,25–28] and not adequately described to judge risk of bias in one study [18]. For potential risk of bias from selective reporting, only one study [21] indicated that a protocol was available by providing the trial registration number. Two studies [21,23] did not indicate any other potential threats to validity, two [26,27] did not provide an adequate description to judge potential risk of bias on this item, and eight [17–20,22,24,25,28] discussed other potential risks of bias.

The quality assessment of prospective observational studies showed that overall, 75% of these studies were of moderate quality and 25% were of weak quality; we found no studies of strong quality. 'Selection bias' was the domain in which the studies performed best, and 'data collection' was the worst performing domain. More than 70% of the studies used risk perception measures that were not validated.

Discussion

Cancer risk perception is related to quality of life and health behaviours [7], and the use of educational tools aimed at improving risk perception is becoming more common. The results from this review show that there is no clear evidence to support the effectiveness of educational interventions to improve subjective perception of cancer risk. Despite favourable results from prospective studies, pooled results from RCTs showed that, both in the short and long term, educational interventions did not have a statistically significant impact on level, accuracy or rating of perceived risk perception. The majority of included studies was of moderate quality, and selection bias was the domain where most studies (both RCTs and observational studies) performed best.

This review is the first, to our knowledge, to summarise the impact of educational interventions for people with cancer or those at high or moderate risk of cancer, across all types of educational interventions and cancers. Most previously published reviews looked at only one type of educational intervention [10,11,57–59] such as genetic counselling or focused on one type of cancer [60]. One strength of our review was the inclusion of all study designs, as both RCTs and observational studies provided a different perspective. The diversity of educational interventions and risk perception summary measures from the included studies means that some caution is needed in the interpretation of the pooled data. To address this issue, we classified risk perception using three end points (level of risk perception, risk accuracy and risk rating), and we also separated short-term and long-term effects where appropriate. However, our pooled RCT results consistently showed that cancer educational interventions do not have a statistically significant impact on perceived risk.

Our review also has several limitations. First, a search of the grey literature, particularly conference abstracts and unpublished theses, was not conducted, so publication bias could not be completely eliminated. Second, there was an overrepresentation of patients with breast cancer and therefore of women. The generalisability of results to other types of cancer and to men is unclear. Third, in our quality assessment, we relied on information about methodology as reported in the articles. For observational studies, information about confounding and blinding was often missing; we then scored these studies as 'moderate' methodological quality without contacting authors for verification. Fourth, some RCTs in our review could not be pooled with results from other studies because of missing data or different measures. Omission of these studies may have influenced the overall pooled results and thus the conclusions of the review. To provide more information about these individual studies, we included brief details on their findings in our manuscript text. Fifth, by combining all the different types of educational interventions, there is a risk that the effect of a well-conducted study with proven effectiveness might be hidden. Therefore, we ensured that results for individual studies were also provided. Finally, when examining risk accuracy, different methods for defining, measuring and analysing the data were used across studies, influencing our ability to compare changes from baseline.

Unlike the RCTs, many of the prospective observational studies included in this review demonstrated statistically significant improvements in the level, accuracy and rating of perceived risk. It is unclear why there was a discrepancy between the results of RCTs and observational studies. Compared with RCTs, observational studies are considered more prone to bias, such as confounding and publication bias [61], so we cannot exclude the possibility that bias influenced the observed effects in the observational studies. However, two studies published in The New England Journal of Medicine in 2000 found that observational studies and RCTs overall produced similar results [62,63]. The authors of these findings cast doubt on the idea that 'observational studies should not be used for defining evidence-based medical care' and that RCT' results are 'evidence of the highest grade' [62,63]. In addition, research by Shrier *et al*., published in the American Journal of Epidemiology [64], concluded that 'excluding observational studies in systematic reviews a priori is inappropriate and internally inconsistent with an evidence based approach.' A 2001 study published in the Journal of the American Medical Association concluded that 'discrepancies beyond chance do occur and differences in estimated magnitude of treatment effect are very

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common' between observational studies and RCTs [65]. Another possible explanation could be that the types of interventions differed somewhat across the two study designs, as a higher proportion of the observational studies (68%) used genetic counselling interventions, compared with 36% of RCTs. Previous systematic reviews and meta-analyses have shown that genetic counselling may be effective in improving risk perception [59], particularly for breast cancer risk [57,58]. However, a systematic review by Braithwaite *et al*. [10] found that although genetic counselling improved the knowledge of cancer genetics, it did not alter the level of perceived risk. Similar to our study results, they found the evidence of effectiveness from observational studies but not from RCTs [10].

Perception of cancer risk has been reported to be relatively resistant to change over time [66,67]. This could be explained by two factors: first, people often find information on health risks difficult to understand [68,69]. According to the UK National Cancer Institute [70], people do not always have a clear understanding of the risks of cancer or of the likelihood of various outcomes of cancer screening tests and treatments. This could be due to the complexity that is often inherent in information about risk, as well as the need for adequate numeracy and literacy skills to understand the information. Second, communication of risk information to consumers requires clear presentation and wording; however, there is no consensus as to which format is most effective in terms of facilitating patient understanding of risk information [68].

This review captured an array of different intervention formats, ranging from standard genetic counselling to information aids. The majority of studies focused on genetic counselling with an informational approach delivered by genetic counsellors, clinical geneticists, nurses or surgeons. A few studies used a combination of educational components and psychological support or were solely psychological in nature (Table 1). Overall, few studies had a well-articulated, theoretical basis on which the intervention was designed [26,46,49]. It is likely that differences in the format and design of interventions contributed, at least in part, to the variation in our review results. Further studies should ideally base their intervention on a psychological framework, as this may be useful in understanding the way people form personal perceived risk beliefs.

Many studies in this review used single-item measures of risk perception. This is consistent with the findings of a recent review by Tilbert *et al*. [71], which discussed the one-dimensional character of risk perception measures (i.e. measuring magnitude or frequency of risk but not both). In this review, it is not known to what extent some of the heterogeneity or non-significant results are related to the measure used to assess perceived risk. However, it is clear that standardising and validating multidimensional perceived risk measures would be of benefit to the field, particularly when comparing outcomes across studies. In addition, further research on risk perception measures should also consider the way people cope, contextualise and tolerate uncertainty.

Cancer patients or people at moderate or high risk of cancer often overestimate their risk of developing cancer. Although acknowledging that there is still uncertainty about the accuracy of objective cancer risk estimates, there is evidence that improving cancer risk perception has several health benefits. Hopwood suggests that a person's understanding of their cancer risk plays an important role in influencing risk management and health-related decision-making [72]. Evaluating risk perceptions is also important in that it can encourage more appropriate health care behaviours, as people who overestimate their risk may perform excessive preventive strategies whilst those with a tendency to underestimate their risk may not adhere to clinical recommendations. In addition, risk information can be useful for the clinician to facilitate discussions regarding risk management, screening and prevention [73,74].

Analyses of predictors of change in risk perception indicated that several variables such as baseline risk perception, age, ethnicity and cancer-related worry were associated with changes in risk perception. Our findings are similar to a review of perceived risk and breast cancer screening [75], which found weak but statistically significant associations between perceived risk and age, ethnicity and breast cancer worry. Information about which factors predict changes in perceived risk could help clinicians and researchers tailor the design of interventions that are relevant to and appropriate for particular groups.

Many challenges remain in improving cancer risk perception. Our review shows that the measurement of perceived risk is often one-dimensional, non-standardised and reliant on the use of non-validated measures. Further research should focus on the development of new measures for cancer risk perception and test whether a multidimensional measure, combining different elements of risk perception, is feasible and adequate. Risk accuracy appears more amenable to change than mean perceived risk or risk rating, but this also needs further investigation. As demographic characteristics and psychosocial factors influence changes in perceived risk, future studies should integrate these factors into the design and implementation of educational interventions. Most of the published literature has focused on breast cancer, so studies in other cancers and particularly among men and people of diverse socioeconomic and cultural groups would help to assess the generalisability of findings. Finally, given the promising results from many observational studies with 'pre and post' study designs, further investigation of well-designed educational interventions using good quality, randomised controlled trials is warranted. These future research directions will help to clarify the effectiveness of educational interventions for improving cancer risk perception.

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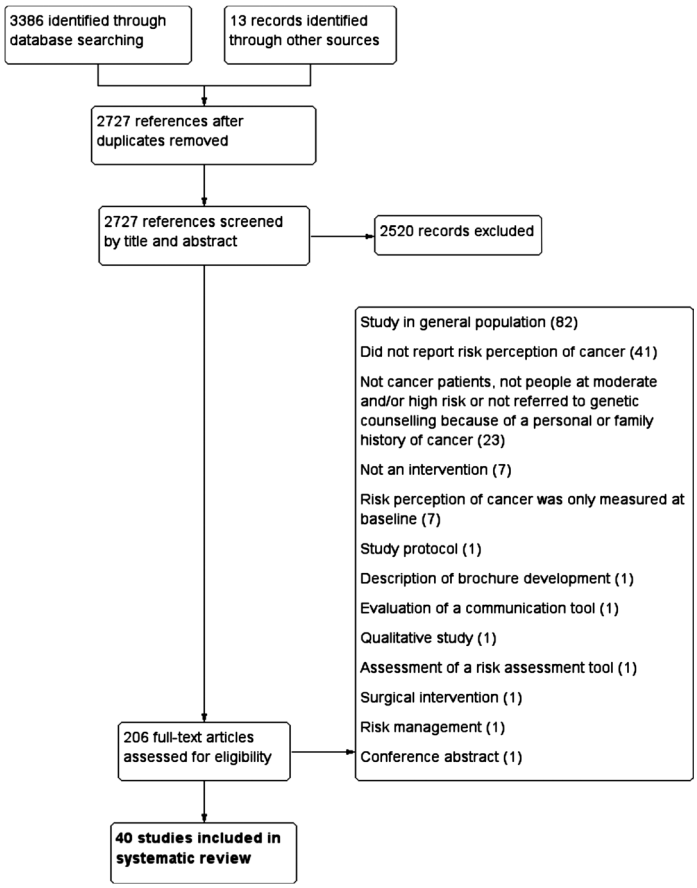
Appendix A. Search strategy in Medline

Question components and relevant search terms	Type of terms: Free text	Type of terms: MeSH
The population: people affected by cancer or at moderate/high risk of cancer		
1. exp. Neoplasms		×
2. Neoplasm*.tw.	×	
3. cancer*.tw.	×	
4. tumo? r*.tw.	×	
5. ((neoplasm*ORcancer*OR tumo? r*)adj3(relapse* OR recurrence*)).tw.	×	
6. or/1–5		
Interventions: educational interventions		
7. education/		×
8. counselling/		×
9. exp. patient education/		×
10. patient education handout/		×
11. (health adj3 education).tw	×	
12. ((education*)adj3(intervention* OR programme? e* OR tool* OR strateg*)).tw.	×	
13. ((patient*)adj3(information* OR instruction* OR training OR toolkit OR website OR handout)).tw.	×	
14. or/7–13		
Outcomes: risk perception, risk knowledge		
15. exp risk/		×
16. ((risk*) adj3(understanding OR perception OR communication OR counsel? ing OR presentation OR recall OR accuracy OR knowledge OR education)).tw.	×	
17. ((perceived OR subjective) adj3 (risk*)).tw.	×	
18. or/15–7		
19. and/6,14,18		

Appendix B. Study flow chart



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Supporting information

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