

The impact of informing diagnosis on quality of life in patients with cancer: A systematic review and meta-analysis

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Research article

Keywords: awareness of diagnosis, cancer, disclosure of diagnosis, meta-analysis, quality of life, systematic review

Posted Date: March 5th, 2020

DOI: <https://doi.org/10.21203/rs.3.rs-16112/v1>

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Version of Record: A version of this preprint was published on July 2nd, 2020. See the published version at <https://doi.org/10.1186/s12885-020-07096-6>.

Abstract

Objective To assess the impact of informing diagnosis and disease status on the quality of life in patients with cancer **Method** We searched the follow databases, Pubmed, CENTRAL(Cochrane Central Register of Controlled Trials), PsycINFO, WEB OF SCIENCE, Embase, CBM (Chinese Biomedical Literature database), WANFANG database (Chinese Medicine Premier), and CNKI (China National Knowledge Infrastructure). And the terms used are as follows: neoplasm, cancer, tumour, tumor, carcinoma, disclosure, truth telling, breaking bad news, knowledge, knowing, awareness, quality of life, QOL. Pairs of reviewers independently screened documents and extracted the data. Meta-analysis was conducted by Revman 5.0 software. **Results** There were 11740 records retrieved from databases and 23 studies were included finally. Meta-analysis of informed and uninformed cancer patients revealed no differences in both the general quality of life and symptoms of fatigue, pain, dyspnea, insomnia, appetite loss and diarrhea ($P>0.05$). Additionally, no difference in physical function, role function, cognitive activity and emotional function between the above 2 groups($P>0.05$) were found. On the vitality area, the patients who were totally informed about their diagnosis had higher vitality than the uninformed patients. However, patients aware about their illnesses seemed to get lower scores in social function. Between the partly informed of the diagnosis and uninformed cancer patients, there were no differences in general quality of life, function domains and disease-related symptoms ($P>0.05$). **Conclusion** Informing the cancer patients their diagnosis may not have a bad effect on their quality of life. PROSPERO registration number CRD42017060073.

Background

An estimated 17.5 million new cancer cases and 8.8 million cancer deaths occurred in 2015 worldwide.^[1] The health care providers were usually reluctant to tell their patients about the diagnosis of cancer.^[2, 3] Although it is ethical to inform the patients the diagnosis and disease status, plenty of physicians and patients' relatives still believed that concealing patients' diagnosis and disease status was significant for the prognosis of the patients.

Many researchers were interested in this topic as well. One study showed that patients' awareness of disease status significantly increased the rate of psychiatric disorders such as depression and anxiety.^[4] However, another research revealed that awareness of disease status helped to decrease the occurrence of depression and anxiety in patients with end-of-life cancer.^[5] A systematic review published in 2015 tried to confirm the influence of awareness of disease status on the quality of life in the patients with metastatic cancer, while mixed findings were shown on the association.^[6] However, there is no systematic review with meta-analysis to assess the impact of awareness of diagnosis on quality of life(QoL) for patients with cancer.

In this review, we will systematically collect and review the studies focusing on the association between disclosure of diagnosis for cancer patients on QoL, and conduct a meta-analysis to quantitatively present the association by pooling the effect estimates.

1. Method

1.1 Inclusion and exclusion criteria

The following inclusion criteria were used to optimize appropriate selection of articles: (1) written in the English or Chinese language; (2) articles that explored the concept of awareness of disease status among patients with cancer; (3) articles that explored the impact of disease awareness on patients' quality of life; (4) randomized controlled studies, cohort studies or case control studies. The following exclusion criteria were used: (1) the conference abstract; (2) unavailable full text.

1.2 Patient and public involvement

No patient involved.

1.3 Literature retrieval and screening

We searched the following databases, Pubmed, CENTRAL (Cochrane Central Register of Controlled Trials), PsycINFO, WEB OF SCIENCE, Embase, CBM (Chinese Biomedical Literature database), WANFANG database (Chinese Medicine Premier), and CNKI (China National Knowledge Infrastructure). And the terms used are as follows: neoplasm, cancer, tumor, tumor, carcinoma, disclosure, truth telling, breaking bad news, knowledge, knowing, awareness, quality of life, QOL. And we also hand searched reference lists of obtained articles. If we couldn't obtain the articles, we would e-mail the author. Pairs of reviewers independently screened literatures and the third reviewer resolved the disagreement. And the terms above had been complementary searched in February, 2018.

1.4 Data extraction and management

Pairs of reviewers independently extracted the data of included studies. The following data was extracted: first author, publication year, country, journal, the setting where the research was carried out, the time when the study began and ended, the definition of exposure in the research, study design, financial support, conflicts of interests, patients' characteristics and quality of life. The third reviewer resolved the disagreement.

1.5 Primary and secondary outcome measures

The included trials measured self-reported participant measures of QoL as primary or secondary end points.

Primary outcomes

General quality of life;

Secondary outcomes

1) QoL domains:

- i. physical function (e.g. performance of self-care activities, mobility, physical activities);
- ii. social function(e.g. performance of work or household responsibilities, social interactions);
- iii. role function(e.g. performance of daily life, amusement, hobbies);
- iv. emotional function(e.g. sadness , anxiety, depression, negative affect);
- v. cognitive activity(e.g. performance of focusing attention, memorizing);
- vi. vitality (e.g. energy and fatigue);
- vii. economic function(e.g. financial difficulty)

2)Disease-related symptoms (or both)(e.g. fatigue, pain, dyspnea, insomnia, appetite loss, diarrhea).

1.6 Assessment of risk of bias in included studies

Pairs of reviewers independently assessed risk of bias of the included studies by the ROBINS-I assessment tool^[7] for non-randomized studies and the Cochrane risk of bias tool for randomized controlled trials. We resolved any disagreements by discussion or consulting the third reviewer.

1.7 Assessment of publication bias

If we included at least 10 studies in a meta-analysis, we generated funnel plots of effect estimates against their standard errors (on a reversed scale) by using Review Manager software (RevMan). We assessed potential risk of publication bias through visual analysis of funnel plots, with roughly symmetrical funnel plots indicating low risk and asymmetrical funnel plots hinting at high risk of publication bias. One should be aware that this is a rather subjective judgement, that funnel plot asymmetry might also arise from other sources and that publication bias need not lead to asymmetry in funnel plots. We further attempted to avoid publication bias by searching trials registries and conference proceedings for unpublished studies. We addressed duplicate publication bias by including only one studies with more than one publication. If we had doubt about whether multiple publications referred to the same data, we attempted to contact trial authors by email.

1.8 Grading of the evidence quality

Based on the results of the systematic review, the GRADE system is applied to evaluate the quality of evidence, which can be divided as follows: high quality (or A) : being very confident that the real effect value is close to the estimated effect value; Moderate quality (or B) : having moderate degree of confidence in the estimated value of the effect, the real value may be close to the estimated value, but there is still the possibility of large difference between the two groups; Low quality (or C) : the degree of confidence in the effect estimate is limited, and the true value may be quite different from the estimate;Very low quality (or D) has little confidence in the effect estimate, and the true value is likely to be very different from the estimate. Although evidence based on RCT is initially classified as high quality, confidence in such evidence may be diminished by five factors :(1) limitations of the study;(2) inconsistency of research results;(3) indirect evidence;(4) inaccurate results;(5) publication bias. Based on

the same three factors, the evidence can be upgraded;(1) large effect value;(2) dose-effect relationship exists;(3) possible confounding bias may reduce efficacy.

1.9 Strategy for data synthesis

Measures of treatment effect: We analyzed continuous outcomes as standardized mean differences (SMD) between groups with a 95% CIs. For assessment of heterogeneity, we determined statistical heterogeneity by using the χ^2 test. If heterogeneity was little ($I^2 < 50\%$, $P > 0.05$), we had used the fixed effects model to calculate the combine effect. If heterogeneity was large, ($I^2 \geq 50\%$, $P \leq 0.05$), we had used the random effects model to combination of the studies. For assessment of reporting biases, we investigated for publication bias and other reporting biases by the using funnel plots.

2. Results

2.1 Results of the search

Through a comprehensive literature search, we identified and screened for retrieval of 11740 references. We excluded a total of 11608 references based on the title and abstract. And after screening the full text, a total of 108 references were excluded. Subsequently, 23 references were included. See Figure 1 for a flowchart of the search process.

2.2 Overall study characteristics

The 23 included studies were all cohort studies. In all, 3322 (range 10 to 352) participants were enrolled. For detailed information on overall study characteristics see Table 1.

2.3 Risk of bias in included studies

The included studies were assessed for risk of bias using the ROBINS-I assessment tool. For each trial the risk of bias is detailed in Table 2.

2.4 Meta analysis results

2.4.1 Overall quality of life Change in QoL from baseline following a totally informed of diagnosis intervention showed no difference compared with uninformed in 1593 study patients (SMD 0.12; 95% CI-0.09 to 0.34), and no difference between partly informed of diagnosis and uninformed of diagnosis in 219 participants (SMD 0.23; 95% CI-0.26 to 0.72). The details see Figure 2 to Figure 3.

2.4.2 Role function Meta-analyses of comparing totally informed of diagnosis with control intervention did not show a difference in role function among 1250 patients. And it was the same with partly informed of diagnosis intervention. See Table 3 for detailed information.

2.4.3 Cognitive activity we found no significant effect of totally informing cancer patients of diagnosis in cognitive activity. See Table 3 for detailed information. We found no significant effect on cognitive

activity in cancer patients that were totally informed of diagnosis.

2.4.4 Physical function By comparing the score between totally informed of diagnosis intervention with uninformed of diagnosis intervention , we observed no difference in 1150 cancer patients. Get more information in Table 3.

2.4.5 Social function Totally informed of diagnosis intervention did worse and was significantly effected compared to uninformed of diagnosis intervention among 2130 cancer patient (SMD 0.63; 95% CI 0.18 to 1.09). But there was no difference between partly informed of diagnosis intervention and totally uninformed of diagnosis intervention (SMD 0.18; 95% CI -0.15 to 0.51) at 296 patients. See Figure 4 and 5for forest picture.

2.4.6 Vitality The significant effect of totally informed of diagnosis were better than uninformed of diagnosis in role function among 212 cancer patients (SMD 2.22; 95%CI 0.11 to 4.33). As to partly informed of diagnosis versus totally uninformed of diagnosis, there was no study found on this research. More information is in Figure 6.

2.4.7 Emotional function There showed no difference between totally informed diagnosis intervention and partly informed diagnosis intervention compared with totally uninformed of diagnosis intervention. See Table 3 for detailed information.

2.4.8 Economic difficulty We observed significant effect of totally informed of diagnosis on economic function was better than uninformed of diagnosis in 1123 participants looking at the change in score across instruments from baseline to follow-up (SMD 0.45; 95%CI 0.08 to 0.82) . The uninformed of diagnosis cancer patients more often felt economic difficulty than totally informed of diagnosis patients. See Figure 7 for detailed information.

2.4.9 Disease-related symptoms we observed no significant effect between totally informed of diagnosis and uninformed of diagnosis in fatigue, pain, dyspnea, diarrhoea, constipation, appetite loss, insomnia, nausea and vomiting . And the details were all shown in Table 3 and Table 4.

2.5 Grading of evidence quality

The results based on systematic reviews were graded very low and low. The details were shown in Table 5

2.6 Publication bias

We included 10 studies in the meta-analysis of overall quality of life between totally informed of diagnosis and totally uninformed of diagnosis in cancer patients, so we generated a funnel plot of effect estimates against their standard errors (on a reversed scale) by using Review Manager software (RevMan). The funnel plot was nearly symmetrical and every meta-analysis exited negative and positive

results. Therefore it had little possibility exiting publication bias in this study. See Figure 8 for detailed information.

3. Discussion

3.1 Summary of main results

We included 23 trials with 3322 participants distributed over totally informed of diagnosis, partly informed of diagnosis and uninformed of diagnosis groups. The conference abstracts and unavailable full text were excluded due to the lack of available information. Almost all the included studies' were of low quality, among which 20 studies had an existing bias due to confoundings (for examples, age, degree of education, and so on) and only 5 of them had an adjusting analysis, while there were still 3 studies without a bias due to consistence in their confoundings and baselines.

Through the meta-analysis, the cancer patients who were totally informed or uninformed of the diagnosis had no differences in the both the general quality of life and symptoms of fatigue, pain, dyspnea, insomnia, appetite loss and diarrhea ($P > 0.05$) and there were also no difference in physical function, role function, cognitive activity and emotional function between the above 2 groups ($P > 0.05$). However, on the vitality area, the patients totally informed about their diagnosis had higher vitality than the uninformed patients'. . But patients who knew their illnesses seemed to get lower scores in social function. Between the group of patients that were partly informed about the diagnosis and the uninformed cancer patients, there were no differences in general quality of life, function domains and disease-related symptoms ($P > 0.05$).

3.2 Implications for practice

Cancer is always a special study around the world. And the quality of life among cancer patients can be an important concern in their therapeutic process^[8-11]. Furthermore, the issue whether cancer patients should be informed of their diagnosis has long been debated^[12]. Because of the differences of the notions, some people intended to tell the truth to their relatives for their rights to know, while the other would say the white lies for worries about the patients' psychology defense^[12,13-16]. Our research' results implicated disclosure of cancer diagnosis, partly informed of or lack of it, had no significant impact on health related quality of life in cancer patients. Therefore it indicated that physicians could inform the patients of their illnesses and educate them, which would make them understand the cancer well and could get the families, patients and the doctors in charge together to make the personalized and systematic therapy plans and evaluate the prognosis accurately^[17]. Furthermore, concealing the truth might render patients suspiciousness, gloomy and leading to a depression that could promote the progression of the tumor. Nonetheless, when exposing the truth to the patients, it would be better that the clinicians educated patients and their families separately. Because the patients need more knowledge about the cancer to fight against it bravely and optimistically, while their families need more patience and

confidence to support the patients^[17-20]. And it may be a research direction in clinical practice for cancer patients' education.

3.3 Implications for research

This systematic review and meta-analysis of 23 trials on the effect of health-related quality of life on cancer patients informed of their diagnosis provides the evidence that cancer patients' knowledge about the diagnosis may have no effect, irrespective of the varying follow-up periods, on the general quality of life and symptoms of fatigue, pain, dyspnea, insomnia, appetite loss, physical function, role function, cognitive activity and emotional function and may have beneficial effects on the vitality area and social function.

Further research is required to investigate the best way to tell the truth. Maybe from Ruifen Zhang 2016^[21], Fang Ding 2008^[22], Xiuling Wang 2006^[23] we can suppose that delivering the truth to cancer patients and comprehensively nursing, specially mental nursing, could be beneficial to their quality of life. However, whether it has difference is still unknown. Furthermore, it would be better if there were more research on different cancer types.

Quality of life is an important measure of cancer survivorship. But because of the quantities of scales, the heterogeneity is large and makes the comparisons of findings between trials extremely difficult. Therefore maybe health-related quality of life scales can be standardized in the future. Our result was consistent with Aggarwal A^[7]'s.

3.4 Strengths and limitations of this study

As far as we know, this is the first systematic review and meta-analysis that investigates whether informing cancer patients about their diagnosis will have some effects on their quality of life.

The results of this study will give clinicians and patients' family some enlightenment on communication with cancer patients.

Our conclusion will rely on both the quality and quantity of the original studies available for review.

4. Conclusion

Informing the cancer patients about their diagnosis may not have a bad effect on their quality of life. But more studies based on high quality evidences are still required.

Abbreviations

EORTC = European Organization for Research and Treatment of Cancer, GRADE = Grading of Recommendation, Assessment, Development and Evaluation, NOS = Newcastle-Ottawa Scale, SMD = standardized mean difference.

Declarations

Ethics approval and consent to participate

Not applicable.

Consent for publication

Not applicable.

Availability of data and materials

No additional data is available.

Funding

There was no financial support in the study.

Competing Interests

None.

Authors' contributions

Conceived and designed the research: MW, XL, JW and JZ. Performed the study (including literature search, classifying the CRs and extracting data): MW, XL, ZLi, JW. Analyzed data: MW and MNL. Drafted the manuscript: MW and MNL. Modified the manuscript: JZ.

Acknowledgements

We would like to thank Dang Wei (the PhD candidate from Karolinska Institutet, Sweden.) for his invaluable assistance with his advice on data analysis.

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Tables

Due to technical limitations the tables are available as a download in the Supplementary Files.

Figures

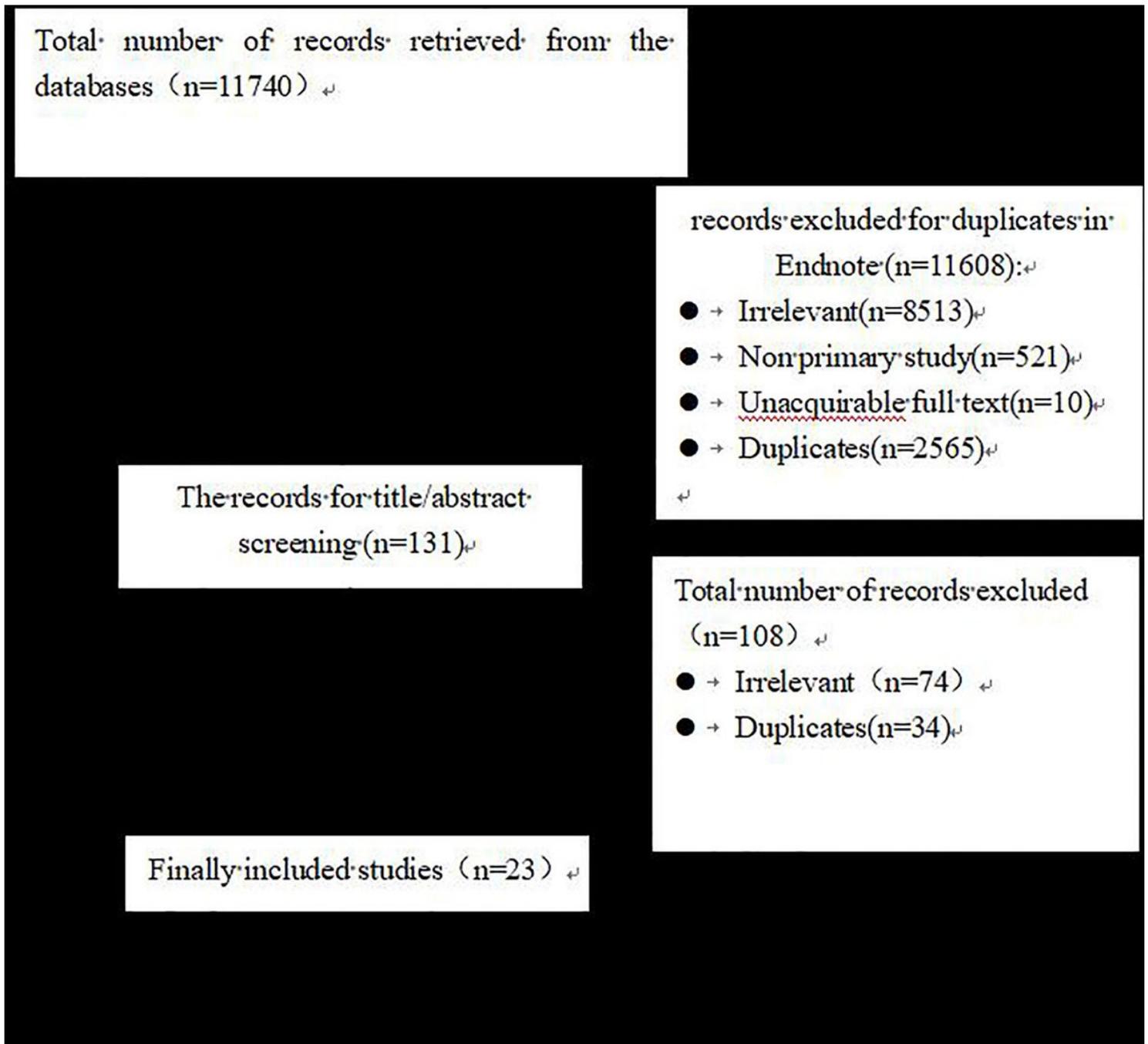


Figure 1

Study flow diagram.

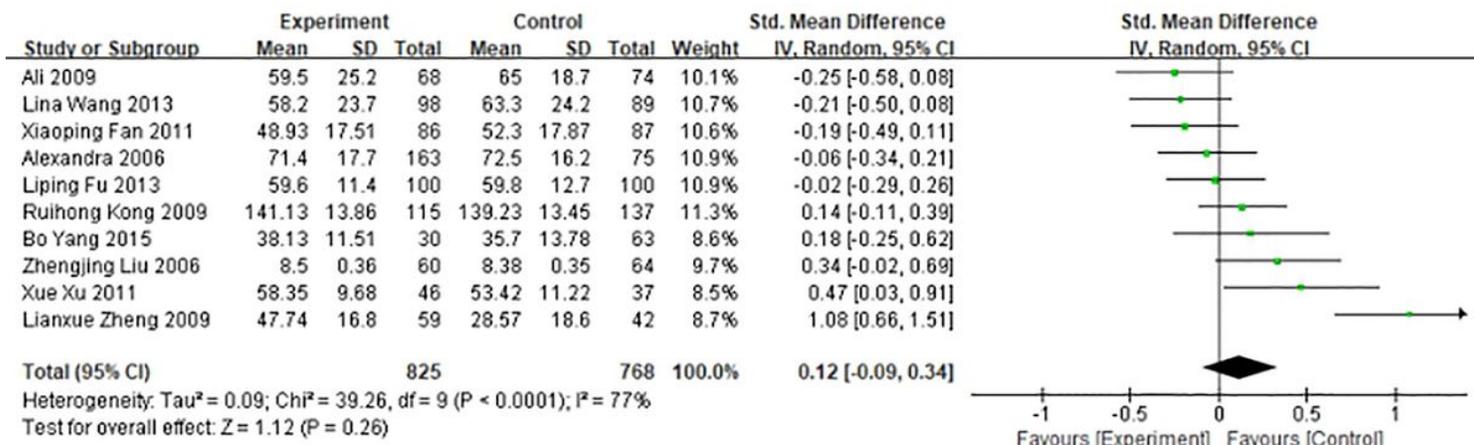


Figure 2

Forest plot of overall quality of life between totally informed of diagnosis and totally uninformed of diagnosis in cancer patients

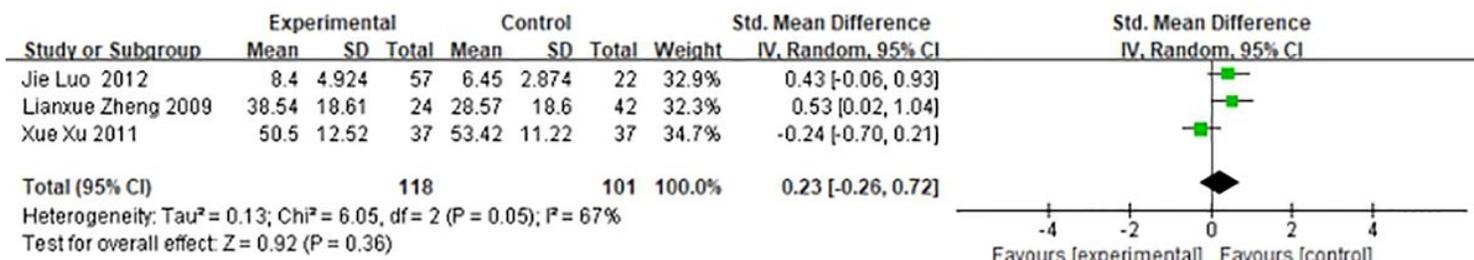


Figure 3

Forest plot of overall quality of life between partly informed of diagnosis and totally uninformed of diagnosis in cancer patients

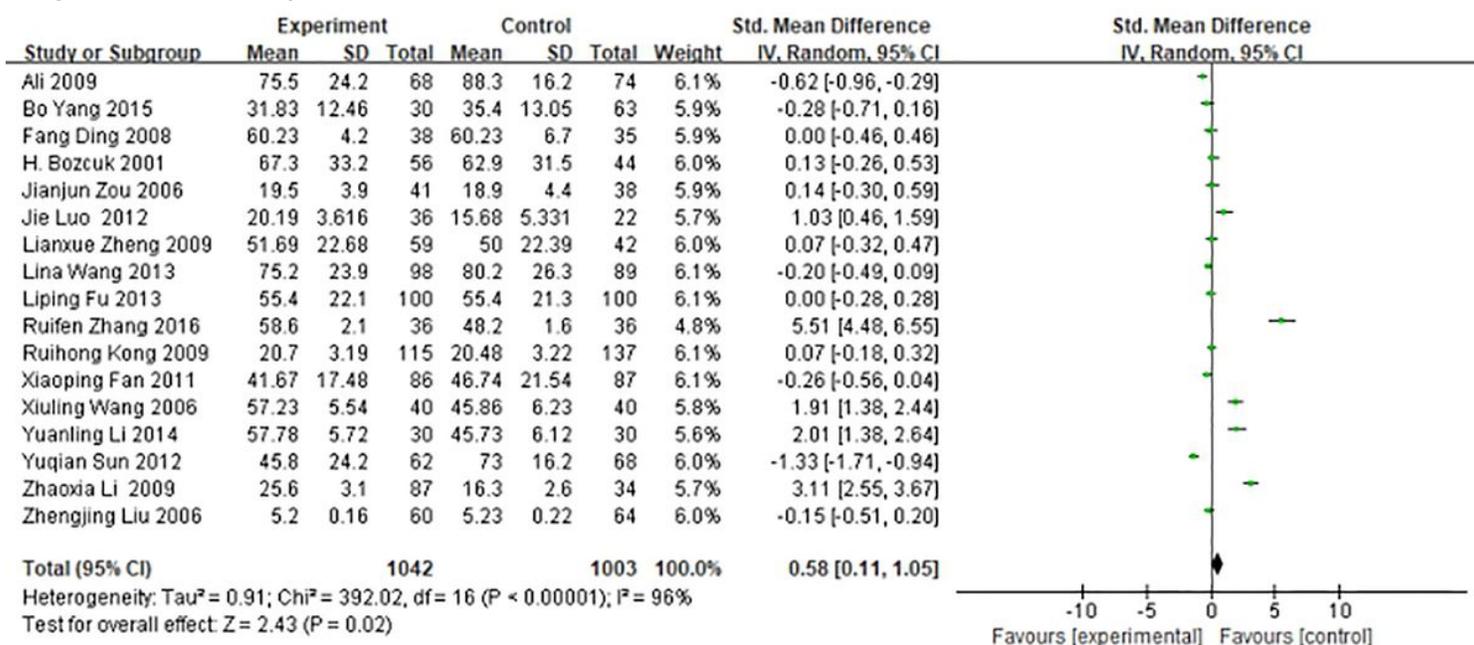


Figure 4

Forest plot of social function between totally informed of diagnosis and totally uninformed of diagnosis in cancer patients

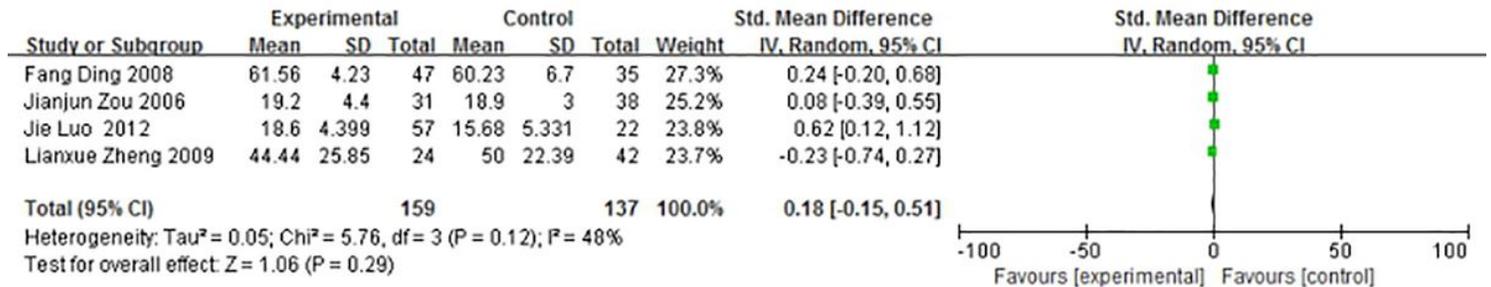


Figure 5

Forest plot of social function between partly informed of diagnosis and totally uninformed of diagnosis in cancer patients

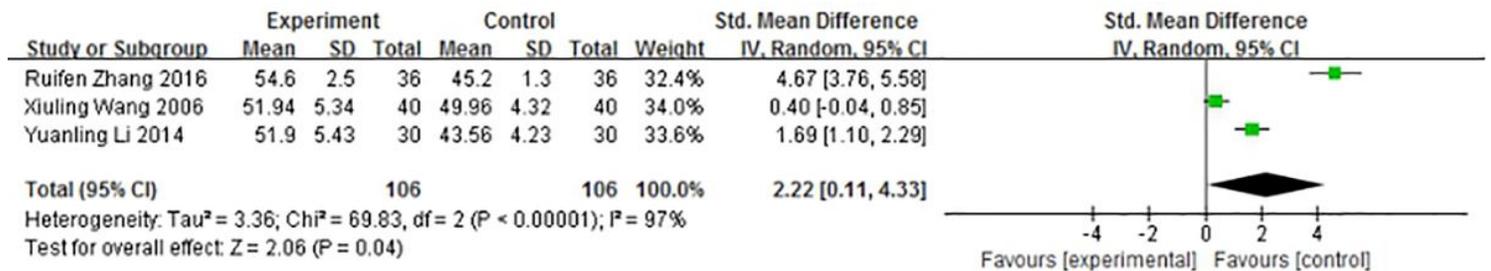


Figure 6

Forest plot of vitality between totally informed of diagnosis and totally uninformed of diagnosis in cancer patients

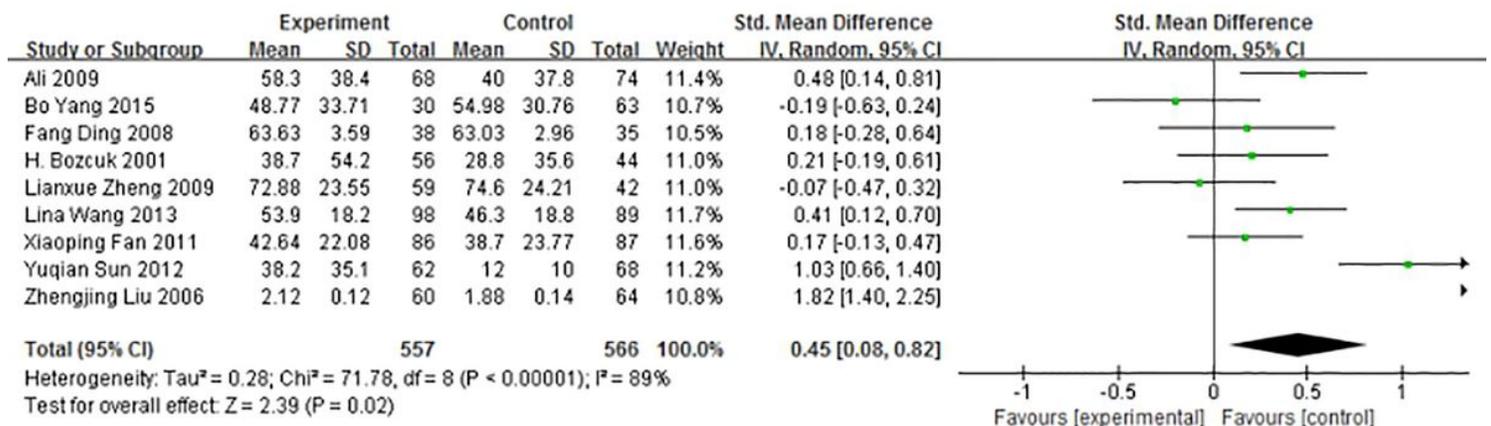


Figure 7

Forest plot of Economic difficulty between totally informed of diagnosis and totally uninformed of diagnosis in cancer patients

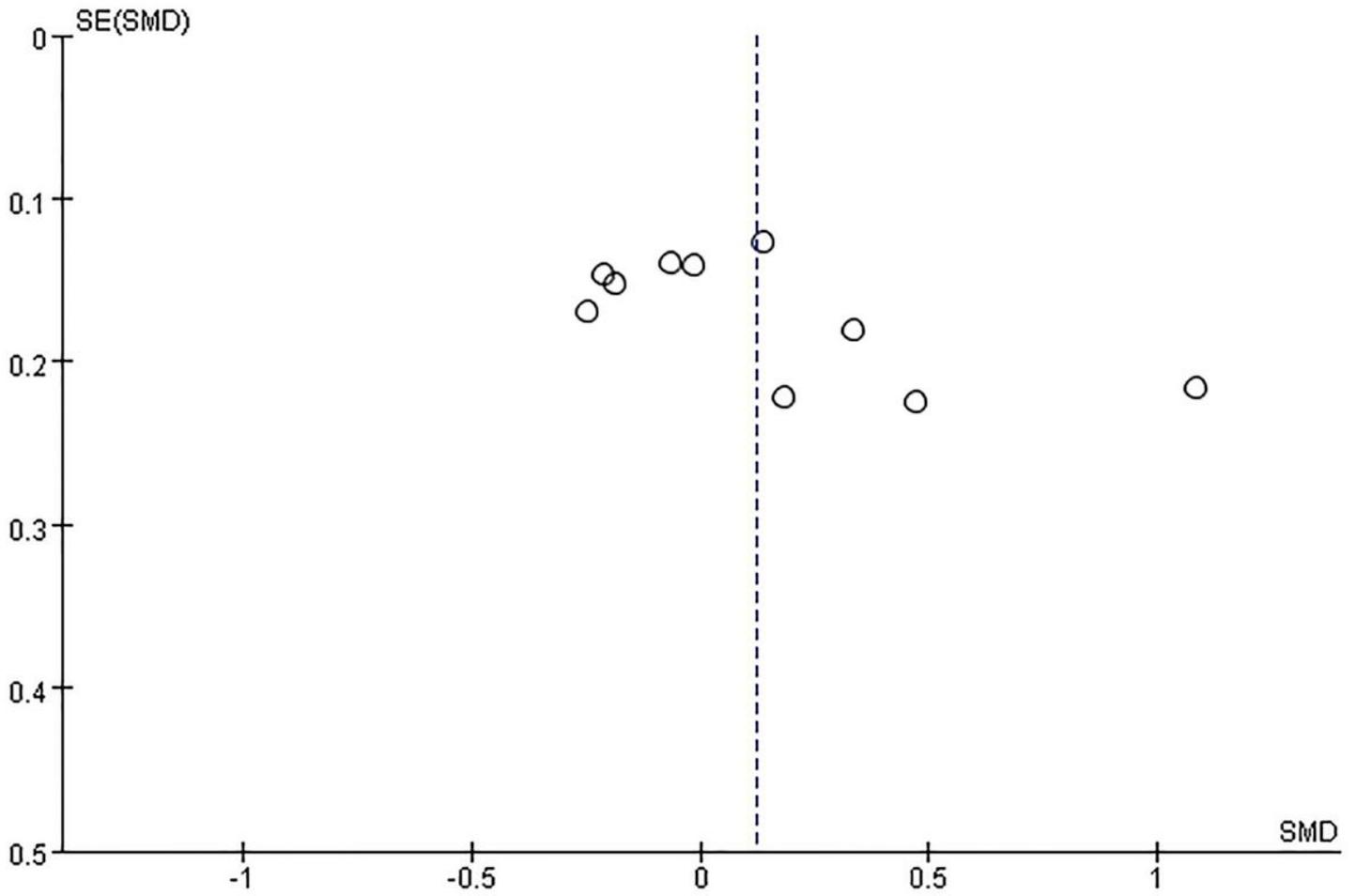


Figure 8

Funnel plot in the meta-analysis of overall quality of life between totally informed of diagnosis and totally uninformed of diagnosis in cancer patients

Supplementary Files

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