Systematic Review and Meta-Analysis of Health Related Quality of Life and Reported Experiences in Patients With Abdominal Aortic Aneurysm Under Ultrasound Surveillance

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WHAT THIS PAPER ADDS
Screening programmes are excellent ways to detect and prevent diseases, and with progress in medicine and health care and with an ageing population they will most likely be more common in the future. But screening is not only about the physical aspect of finding and preventing a disease, and thus prolonging life. It also involves psychological aspects, with a potential to harm. The findings of this study show that concerns regarding such negative effects are unfounded but that there are still areas for improvement when it comes to how those identified of having an abdominal aortic aneurysm are informed.

Objective: Most screening and opportunistically detected abdominal aortic aneurysms (AAA) are small and kept under surveillance for several years before preventive surgery. Living with the diagnosis of an AAA may have an influence on the patient’s life. Thus, it is important to study patients’ experiences so that the screening process and follow up care are adapted to the patient’s needs. The aim was to review systematically review the current knowledge of the effect on health related quality of life (HRQoL) and patients’ experiences of living with an AAA while under surveillance.

Methods: A systematic literature review of quantitative and qualitative studies, which were quality assessed according to the GRADE system, was carried out. Pubmed, Cochrane, Embase, CINAHL, PsycINFO, and MEDLINE were searched. Narrative synthesis and meta-analysis were performed and reported according to the Preferred Reporting Items for Systematic Reviews and Meta-Analyses statement.

Results: Synthesis and meta-analyses of studies based on the Short Form-36 demonstrated that patients with an AAA consistently rated their general health (GH) lower than controls and conveyed no significant negative impact for patients with an AAA when assessed at follow up and compared with pre-screening. Synthesis and meta-analyses of HRQoL estimates encompassing mental health, anxiety, and depression demonstrated no significant differences for patients with AAA compared with controls, or within the AAA group. Qualitative studies revealed that patients with an AAA felt safe being under surveillance, and receiving a diagnosis of AAA set thoughts and feelings in motion regarding health, ageing, and mortality. Patients’ lack of knowledge about the disease, its progression, and future planning can cause insecurity and worries.

Conclusion: The current evidence does not support a negative impact on HRQoL from being under surveillance for an AAA. Qualitative data indicate that adequate patient information and professional care have the potential to reduce unnecessary worries and concerns in patients with an AAA.

Keywords: Abdominal aortic aneurysm, Health related quality of life, Meta-analysis, Patient experience, Quality of life, Screening, Systematic review

Article history: Received 22 February 2019, Accepted 15 July 2019, Available online XXX /C211

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INTRODUCTION
Screening elderly men for abdominal aortic aneurysm (AAA) has been proven to be effective and cost effective in randomised controlled trials in a large contemporary population based setting,1–5 and is recommended in recent guidelines.6

Please cite this article as: Lyttkens L et al., Systematic Review and Meta-Analysis of Health Related Quality of Life and Reported Experiences in Patients With Abdominal Aortic Aneurysm Under Ultrasound Surveillance, European Journal of Vascular and Endovascular Surgery, https://doi.org/10.1016/j.ejvs.2019.07.021
Most screening and opportunistically detected AAA are small, and patients are kept under surveillance, often for several years, during which the aneurysm slowly expands before reaching the size indicating the need for preventive surgery. Living with the knowledge of having an AAA may have an influence on the patients’ lives and it is important to study their experiences so that the screening and follow-up are tailored to patients’ need for information, education, and care.

The effects on health related quality of life (HRQoL), anxiety, depression, and patients’ experiences of having a small AAA have been evaluated in studies of various designs and in different settings. Well established questionnaires give the opportunity to include many patients and reach reliable and validated results in a practical manner. Interview studies provide the opportunity to explore patients’ experiences and feelings regarding phenomena in an in-depth manner and these methods may be complementary. The aim was to investigate current knowledge of impact on HRQoL and patients’ experiences of living with a small AAA (30–54 mm), while being under surveillance.

**METHOD**

A systematic literature review of quantitative and qualitative studies was performed. The systematic review and quality assessment were conducted using validated guidelines, and reported in compliance with the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) statement. Narrative synthesis was performed for the quantitative and qualitative studies separately, and then converged to one synthesis. Meta-analyses were conducted on suitable quantitative studies.

**Literature search**

The search strategy was based on the search performed by the Swedish agency for health technology assessment (SBU) for the “Report on screening for aortic abdominal aneurysm”. Pubmed, Cochrane, Embase, CINAHL, PsycINFO, and MEDLINE were searched using the following keywords: “Aortic Aneurysm”; “Aortic Aneurysm, Abdominal”; “Abdominal aortic aneurysm”; “mass screening, screening”; “quality of life”; “health related quality of life”; “interview, harm”; “psychological impact”; and “patient experience”. The search covered the period from 1 January 1990 to 31 December 2018, for papers in the English language (Supplementary Fig. S1). Reference lists for included articles were searched manually, but no additional studies meeting the inclusion criteria were found. For the exact search strategy and results, see Supplementary Fig. S1.

**Quality assessment**

The quality assessment of the included studies was performed using validated guidelines and templates from The Joanna Briggs Institute, the GRADE handbook, and SBU. Accordingly, the quality of the quantitative studies was pre-ranked as low, based on their design (observational studies), and the outcomes relevant for this review were assessed for each study and not the overall quality of evidence. The assessment and results were discussed and agreed upon in the writing group (L.L., A.W., M.B., E.J.) (see Fig. 1).

**Synthesis and analysis for studies with quantitative method**

Most of the quantitative studies included used well established questionnaires the 36-Item Short Form Health Survey (SF-36) and the Hospital Anxiety and Depression Scale (HADS). The SF-36 measures physical and mental health and the results give an eight scale profile of functional health and well being scores and psychometrically based physical component summary and mental component summary (MCS) scores. The score for the scales is between 0 and 100 (higher score equals better health). The HADS is a validated questionnaire that detects and measures states of depression and anxiety in the setting of a hospital and medical outpatient clinic. The General Health Questionnaire 28 item (GHQ-28) measures anxiety and depression. By exploring the relationships within and between all included studies, using tabulation, and grouping of results, a narrative synthesis was performed.

**Statistical methods**

Inclusion criteria for the meta-analyses were studies of a similar design, i.e., including either repeat measures (pre- and post-screening) within the AAA group or comparable measures between an AAA and a control group and studies, where it was possible to retrieve the necessary statistical distribution data (standard deviation [SD], standard error [SE], confidence intervals). Diversity of studies was expected concerning study populations and settings; thus, a random effects model for meta-analysis was selected. The aim of the meta-analysis was pooling eligible reported HRQoL estimates from the available studies. Cochran’s Q test (chi square) was used to test for heterogeneity. Heterogeneity was also assessed by I² and τ. The meta-analysis was performed using the Cochrane Collaboration’s RevMan 5.3 tool. Where only p values were reported, the RevMan Calculator was used to calculate the SD (L.L., S.S., A.W.).

**Synthesis for studies with qualitative method**

The studies were analysed in several phases. The key findings from each study were sorted by their original themes, subthemes, and categories. Similar findings were identified and sorted into common themes and subthemes. While synthesising findings across the studies, new themes and subthemes emerged. The findings were then collated with the text of the original studies to confirm that the correct meaning, understanding, and nuances were comprehended. Two authors (L.L. and E.J.) discussed the analysis, and consensus on the findings was reached. The findings were supported by quotations from the original studies.
RESULTS

Studies with quantitative method

Thirteen studies with a quantitative research method were included (Table S1; see Supplementary Material), all observational studies with a case control design. The most common questionnaires used were SF-36 (n = 8) and HADS (n = 5). Eleven studies were performed in a screening setting and had repeated measures, of which seven had pre-screening measures. Two studies included patients under surveillance for opportunistically detected small AAA, and one study included patients with both screening and opportunistically detected AAAs. Three of the studies included both men and women, while the other studies included men only. The control groups in the included studies mainly consisted of participants in screening programmes with a normal aorta.

The quality assessment (Table S1) identified limitations of the overall study structure and reading comprehension, such as not having a clearly formulated aim, a non-clearly described sample, method, and/or results. Several studies did not present confounding factors such as comorbidities.

As two of the largest studies only used five items for General Health (GH) from the SF-36 as a pre-screening measure, the meta-analysis was restricted to the GH scale concerning physical HRQoL. Two studies reported MCS scores from the SF-36 and, together with one study using the similar GHQ-28, these three studies were judged appropriate for meta-analysis regarding mental HRQoL. In the physical assessment one study used a slightly modified SF-36 GH scale, and in the mental assessment a combination of established scales was used. Consequently, effect size was presented with standardised mean difference (SMD). Meta-analyses of four studies measuring GH with SF-36 pre- and post-screening showed that patients with an AAA rated their GH lower both before and after screening, compared with controls. No difference in GH was seen within the AAA group when comparing pre- and post-screening measurements. Heterogeneity was very low (Fig. 2).

None of the studies measuring anxiety or depression (HADS) showed any difference between AAA patients vs. controls, regardless of length of follow up. Only one study measured pre-screening.

Meta-analysis of SF-36 MCS score and GHQ-28 outcomes showed no difference between AAA patients and controls, or within group AAA comparison, pre-screening or post-screening. Heterogeneity was moderate to high (Fig. 3).

Studies with qualitative method

Eight studies with qualitative methods were included (Table S2; see Supplementary Material). Five of the studies were performed in Sweden and one in the Netherlands. Two of the studies were follow ups on included studies. The age range was 63–83 years.

The quality assessment showed an overall lack in describing the researcher’s relation to the sample, pre-understanding in relation to data collection and analysis. The potential for the researcher to influence the study and

Figure 1. PRISMA flow diagram of systematic literature search in PubMed via NCBI (1 January 1990 - 31 December 2018) as detailed in Figure S1 (see Supplementary Material).
for the research process itself to influence the researcher and the interpretations is very sparsely, if at all, acknowledged or addressed.

**Qualitative synthesis results**

Three themes were identified.

(i) **Physical symptoms and exercise** The absence of symptoms sometimes caused feelings of doubt over whether the diagnosis was real and the patient’s own ability to detect illness. When other symptoms occurred (e.g., stomach ache), worries related to the AAA came to mind.36,37 For other patients, the absence of symptoms was experienced as a positive thing, in particular for those who struggled with other diseases.35,36,40 Thoughts and uncertainty about physical activity and exertion were expressed among patients in several studies.33,34,36–38,40 Some limited their physical activities and avoided, for example, heavy lifting because of fear of rupture:34,36,40 “When you are doing something, carrying something very heavy, you think … this is probably not a good idea … you are reminded that you have this defect.”34

(ii) **Reflection on health, ageing, and mortality** Receiving the diagnosis of an AAA caused thoughts and reflections about one’s own health,33–35,38,40 ageing, and heredity: “But … it is hereditary … well … you cannot influence it.”33 “So one is scared of course,

### A General health at prescreen

<table>
<thead>
<tr>
<th>Study</th>
<th>General health (SF-36) AAA group prescreen</th>
<th>General health (SF-36) control group prescreen</th>
<th>General health score (SF-36) in AAA group</th>
<th>Mean general health difference (IV, fixed (95% CI))</th>
<th>Weight</th>
</tr>
</thead>
<tbody>
<tr>
<td>Lesjak 199821</td>
<td>42.9 ± 10 47</td>
<td>45.6 ± 9.6 431</td>
<td></td>
<td>–0.28 (–0.58, 0.02)</td>
<td>10.2%</td>
</tr>
<tr>
<td>Marteau 200424</td>
<td>66.2 ± 22.1 571</td>
<td>69.2 ± 19.8 609</td>
<td></td>
<td>–0.15 (–0.27, –0.04)</td>
<td>70.7%</td>
</tr>
<tr>
<td>Spencer 200426</td>
<td>62.1 ± 14.3 97</td>
<td>64.1 ± 13.2 189</td>
<td></td>
<td>–0.15 (–0.39, 0.10)</td>
<td>15.4%</td>
</tr>
<tr>
<td>Wanhainen 200428</td>
<td>68.8 ± 22.2 24</td>
<td>64.7 ± 22.6 45</td>
<td></td>
<td>0.18 (–0.32, 0.68)</td>
<td>3.8%</td>
</tr>
<tr>
<td>Total</td>
<td>739</td>
<td>1274</td>
<td></td>
<td>–0.15 (–0.25, –0.06)</td>
<td>100.0%</td>
</tr>
</tbody>
</table>

Heterogeneity: $\chi^2 = 2.41$, df = 3 (p = .49); $I^2 = 0$

Test for overall effect: $Z = 3.10$ (p < .0001)

<table>
<thead>
<tr>
<th>Lower in AAA group</th>
<th>Lower in control group</th>
</tr>
</thead>
<tbody>
<tr>
<td>–1</td>
<td>–0.5</td>
</tr>
<tr>
<td>0</td>
<td>0.5</td>
</tr>
<tr>
<td>1</td>
<td>1</td>
</tr>
</tbody>
</table>

### B General health at follow-up (6 weeks to 1 year)

<table>
<thead>
<tr>
<th>Study</th>
<th>General health (SF-36) AAA group at follow-up</th>
<th>General health (SF-36) control group at follow-up</th>
<th>General health score (SF-36) in AAA group</th>
<th>Mean general health difference (IV, fixed (95% CI))</th>
<th>Weight</th>
</tr>
</thead>
<tbody>
<tr>
<td>Lesjak 199821</td>
<td>44.9 ± 115 35</td>
<td>49.4 ± 8.4 89</td>
<td></td>
<td>–0.48 (–0.87, –0.08)</td>
<td>6.2%</td>
</tr>
<tr>
<td>Marteau 200424</td>
<td>64.6 ± 22.2 571</td>
<td>69.1 ± 20.3 609</td>
<td></td>
<td>–0.21 (–0.33, –0.10)</td>
<td>73.8%</td>
</tr>
<tr>
<td>Spencer 200426</td>
<td>64.5 ± 20 97</td>
<td>65.8 ± 20 189</td>
<td></td>
<td>–0.06 (–0.31, 0.18)</td>
<td>16.1%</td>
</tr>
<tr>
<td>Wanhainen 200428</td>
<td>66.3 ± 22.2 24</td>
<td>68 ± 21.3 45</td>
<td></td>
<td>0.08 (–0.57, 0.42)</td>
<td>3.9%</td>
</tr>
<tr>
<td>Total</td>
<td>727</td>
<td>932</td>
<td></td>
<td>–0.20 (–0.30, –0.10)</td>
<td>100.0%</td>
</tr>
</tbody>
</table>

Heterogeneity: $\chi^2 = 3.33$, df = 3 (p = .34); $I^2 = 10$

Test for overall effect: $Z = 3.97$ (p < .0001)

<table>
<thead>
<tr>
<th>Lower in AAA group</th>
<th>Lower in control group</th>
</tr>
</thead>
<tbody>
<tr>
<td>–1</td>
<td>–0.5</td>
</tr>
<tr>
<td>0</td>
<td>0.5</td>
</tr>
<tr>
<td>1</td>
<td>1</td>
</tr>
</tbody>
</table>

### C General health in AAA group over time

<table>
<thead>
<tr>
<th>Study</th>
<th>General health (SF-36) AAA group prescreen</th>
<th>General health (SF-36) AAA group at follow-up</th>
<th>General health score (SF-36) in AAA group</th>
<th>Mean general health difference (IV, fixed (95% CI))</th>
<th>Weight</th>
</tr>
</thead>
<tbody>
<tr>
<td>Lesjak 199821</td>
<td>42.9 ± 10 47</td>
<td>44.9 ± 11.5 35</td>
<td></td>
<td>–0.19 (–0.62, 0.25)</td>
<td>5.5%</td>
</tr>
<tr>
<td>Marteau 200424</td>
<td>66.2 ± 22.1 571</td>
<td>64.6 ± 22.2 571</td>
<td></td>
<td>–0.06 (–0.05, –0.18)</td>
<td>78.0%</td>
</tr>
<tr>
<td>Spencer 200426</td>
<td>62.1 ± 14.3 97</td>
<td>64.5 ± 20 97</td>
<td></td>
<td>–0.14 (–0.42, 0.14)</td>
<td>13.2%</td>
</tr>
<tr>
<td>Wanhainen 200428</td>
<td>68.8 ± 22.2 24</td>
<td>66.3 ± 22.2 24</td>
<td></td>
<td>0.11 (–0.46, 0.68)</td>
<td>3.3%</td>
</tr>
<tr>
<td>Total</td>
<td>739</td>
<td>727</td>
<td></td>
<td>–0.02 (–0.08, –0.13)</td>
<td>100.0%</td>
</tr>
</tbody>
</table>

Heterogeneity: $\chi^2 = 2.67$, df = 3 (p = .45); $I^2 = 0$

Test for overall effect: $Z = 0.47$ (p = .64)

<table>
<thead>
<tr>
<th>Lower at prescreen (AAA)</th>
<th>Lower at follow-up (AAA)</th>
</tr>
</thead>
<tbody>
<tr>
<td>–1</td>
<td>–0.5</td>
</tr>
<tr>
<td>0</td>
<td>0.5</td>
</tr>
<tr>
<td>1</td>
<td>1</td>
</tr>
</tbody>
</table>

Figure 2. Meta-analyses of scale scores for General Health from the Short Form-36 (SF-36), comparing AAA patient with controls at prescreen (A) and at follow-up (B); and evaluating general health development over time in AAA patients (prescreen versus follow-up, C). AAA = abdominal aortic aneurysm; SD = standard deviation; IV = inverse variance; CI = confidence interval.
begins to realise that things happen inside in the body … she (the wife) also sees that we are growing old".36 “You can turn it around and say that, well, if it bursts it bursts and then you’re gone. And it will be good not to have to spend years in care. You have to look on the bright side too".17

(iii) The importance and influence of relatives Most patients said that their relative’s response to knowing about the AAA was positive in the way that it was good it was detected and that the patient was now under surveillance. Some also mentioned that it was of benefit to be accompanied by a relative (wife) when they received the information. However, some men expressed the opposite view, i.e., that they experienced worries from their family members, for example when doing heavier tasks, and thought it was a burden to answer questions about their aneurysm.33–35,38

Uncertainty about what the future holds. Patients expressed concern and uncertainty about the diameter and growth rate of the aneurysm and risk of rupture, especially in the case of AAA growth, while they felt more optimistic and calmer in the case of a stable AAA. Although most were positive about finding out about the AAA and satisfied with the checkups, the feeling of uncertainty in combination with not being able to influence the growth and possible surgery in the future, in some resulted in ambivalent thoughts about the knowledge of having an AAA:34,36

Synthesis

Patients with AAA rated their GH lower than controls, both before and after screening, mostly related to decrease in physical functions. However, no difference was seen before or after screening within the AAA group. No differences in mental scores or anxiety and depression were seen

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Figure 3. Meta-analyses of Mental Component Summary (MCS) scores from Short Form-36 (SF-36) and General Health Questionnaire 28 item (GHQ-28), comparing AAA patient with controls at prescreen (A) and at follow-up (B); and evaluating mental health, anxiety and depression development over time in AAA patients (prescreen versus follow-up, C). AAA = abdominal aortic aneurysm; SD = standard deviation; IV = inverse variance; CI = confidence interval.
between AAA patients and controls, or over time within the AAA group. When patients receive the diagnosis of an AAA, feelings of gratitude that the disease was discovered in time and feelings of security of being under surveillance arose, but it also set thoughts and feelings in motion regarding health, ageing, and mortality. A lack of information and knowledge about AAA, its progression, and future planning cause some patients insecurity and worries.

DISCUSSION

This systematic review and meta-analysis, pooling all available studies with pre- and post-screening HRQoL data in the physical and mental clusters, demonstrated no significant impact on HRQoL from being under surveillance for an AAA. The fact that heterogeneity was very low for studies assessing the physical cluster, and moderate for the studies reporting on the mental cluster, meant the results were judged as reliable. Numerically, the pooled analysis for the mental cluster displayed a small reduction in HRQoL in patients with AAA vs. controls, but the confidence interval for the SMD included zero.

Qualitative studies revealed that patients with AAA not only felt safe being under surveillance and had trust in health professionals, but also indicate that routines for patient information and education can be improved as lack or absence of them can cause patients unnecessary worry and concerns.

HRQoL and patient experience are complex areas to study. By using a systematic literature search and combining studies with different methods, studying closely related aims, the evidence can be strengthened and areas where knowledge is lacking can be identified. The studies measuring HRQoL used the same design, relevant sample, repeated measures, and often used validated questionnaires, while sample size, time to first measure, and follow up varied. Several limitations of this review should be considered: some studies are now quite old; eight of the quantitative studies were published 16—22 years ago and three of the qualitative studies 10 years ago. Patients’ perception of having an AAA may have changed over time; generally, access to information has improved dramatically, endovascular surgical methods have evolved and revolutionised the treatment of AAA, and small AAA structured surveillance routines have been developed. However, a majority of the included studies were performed in a screening setting where the participants were informed about the disease before attending and with structured patient information and follow up procedures in place. Most studies used validated questionnaires with the possibility of age adjustment, which partly limits the importance of the age range between studies.

Important confounding factors, such as smoking and comorbidities, were rarely included. It is likely that increased exposure to smoke related cardiovascular diseases in the AAA group to a great extent explains the observed impaired HRQoL in GH vs. controls with a normal aorta. Another important limitation is the sole use of generic HRQoL questionnaires and that the follow up period seldom reached more than one year. Time from screening/diagnosis to the interview varied, which could result in recall bias. The qualitative studies were all (except one) from Sweden, which limits their transferability to other countries. It is likely that cultural differences occur between countries. Future research needs to explore this further.

Study quality varied, with most studies being of low to moderate quality, but all studies meeting the criteria were included in order to review the current knowledge and provide a complete description on the subject. The quality assessment of the studies was a challenge owing to the fact that guidelines and recommendations from GRADE, used in the quality assessment, derive from the randomised controlled trial as the gold standard. To structure and clarify the assessment of methods used, validated guidelines and templates adapted to observational studies, case control, and qualitative studies were used. According to GRADE, all observational studies are pre-ranked as low, which must be considered in drawing conclusions from this review.

A natural response to finding out one has a disease is to feel concerned, and to reflect on one’s health, ageing, and mortality. The important thing for healthcare is not to cause harm by negatively influence participants’ quality of life by transferring this knowledge. Meta-analysis and synthesis in this review shows no negative impact on mental health, anxiety or depression. The result shows that patients felt safe being under surveillance; however, insufficient information, education, and knowledge about the disease caused insecurity and concerns among some participants. As not all studies described how, what, when, and by whom patients were informed, there is an underlying confounder in the fact that the results also are evaluations of the quality of Information and care the patients received at the hospital or care facility they attended for surveillance. Patients need for information and education varies: some need more and some are content with the safety of being under surveillance. As the results from the study of Tomee et al. show, patients’ knowledge of AAA disease and/or treatment options is quite poor, but they feel safe and content all the same. Nevertheless, the responsibility of healthcare professionals to offer and give this information remains.

CONCLUSION

The results of this systematic review show that the current evidence does not support a negative impact on HRQoL from being under surveillance for an AAA. Qualitative data indicate that adequate patient information and professional care have the potential to reduce unnecessary worries and concerns in patients with AAA. There is need for further well designed quantitative and qualitative studies conducted in several different countries.

CONFLICTS OF INTEREST

None.
FUNDING

Uppsala University and Uppsala University Hospital research funding.

APPENDIX A. SUPPLEMENTARY DATA

Supplementary data to this article can be found online at https://doi.org/10.1016/j.ejvs.2019.07.021.

REFERENCES


