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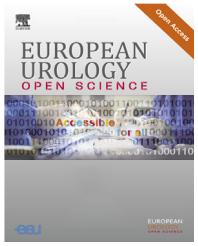

European Association of Urology

Prostate Cancer

Satisfaction with Nurse-led Follow-up in Prostate Cancer Patients—A Nationwide Population-based Study

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Abstract

Background: Satisfaction with nurse-led follow-up among men with prostate cancer is high. However, it is unclear whether all men are satisfied or whether there are men who would benefit from being followed by a urologist or a nurse.

Objective: To investigate the follow-up distribution between urologists and nurses, and whether the high self-reported satisfaction with nurse-led follow-up is independent of other factors such as age or comorbidity.

Design, setting, and participants:

All Swedish men, ≤70 yr of age, with a low-risk prostate cancer diagnosis in 2008, answered a questionnaire 7 yr after diagnosis. The extensive questionnaire included a question on satisfaction with care, answered on a seven-point scale. Participants were divided based on whether they were followed up by a nurse, a urologist, or both.

Outcome measurements and statistical analysis:

Factors that could influence the level of satisfaction were identified as age, education, comorbidity, treatment, disease progression, urinary bother, level of information, and participation in treatment decision. Likelihood ratio tests from ordinal regression were used to test the null hypothesis of similar satisfaction between groups.

Results and limitations: Out of 1288 men, 1137 (88%) answered both the question on who performed the follow-up and the question regarding satisfaction. In all, 350 men reported that they were followed up by nurses (31%), 598 (52%) by urologists, and 189 (17%) by both. No differences in satisfaction where seen between the groups. Approximately 50% were satisfied completely, regardless of who performed the follow-up. Results were not affected by age, educational level, comorbidity, treatment, disease progression, urinary bother, information, or participation in treatment decision. Limitations include the nonrandomized, retrospective design and a potential recall bias.

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Conclusions: Satisfaction with nurse-led follow-up is high, regardless of factors such as age, level of education, comorbidity, and treatment.
Patient summary: Men with prostate cancer can be offered nurse-led follow-up on a regular basis and still maintain their satisfaction with health care.

1. Introduction

The number of men with prostate cancer who need follow-up after curative treatment or are followed in active surveillance (AS) is increasing. As a consequence, health care providers need to adapt to tackle the increasing resources needed. According to the Swedish national guidelines, follow-up can be nurse led as long as it is supervised by a urologist [1].

In the ProtecT study, Wade and colleagues [2] investigated care given at nurse-conducted clinics for men with localized prostate cancer receiving AS. They concluded that nurse-led clinics could relieve the burden at urology wards without jeopardizing the safety of the patients.

We have previously investigated how men with low-risk prostate cancer experienced their medical care and estimated their satisfaction [3]. We found high overall satisfaction with care and no differences in reported satisfaction between men followed by nurses and those followed by urologists [3]. However, men in AS felt less informed about their disease and to a lower degree participated in treatment decision compared with men who underwent curative treatments.

Whether all men with prostate cancer are satisfied with nurse-led follow-up is unclear. The aim of the present study was to investigate the follow-up distribution between urologists and nurses, whether the high self-reported satisfaction with nurse-led follow-up is independent of other factors such as age or comorbidity, and whether we could identify men who would not be satisfied with nurse-led follow-up.

2. Patients and methods

2.1. Study design

All Swedish men registered in the National Prostate Cancer Register, who had been diagnosed with low-risk prostate cancer (Gleason score $\leq$6, prostate-specific antigen <10, and tumor stage <T3) in 2008, were aged $\leq$70 yr, and had undergone radical prostatectomy, radiation therapy, or AS, were invited to participate in the study and received a questionnaire with a letter explaining the purpose of the study. The men were also offered to answer the questionnaire digitally. Of 1720 invited men, 1288 answered the questionnaire [3].

2.2. Data collection

Data were collected between February and October 2015, 7 yr after diagnosis, to include long-term health effects. The questionnaire included 49 study-specific questions and EPIC-26, a questionnaire that assesses functional outcomes in men with prostate cancer. EPIC-26 has previously been described in detail [4]. The questionnaire included questions about the patients' experience at the time of diagnosis and follow-up, alcohol consumption, physical activity, treatments, comorbidity, as well as psychological comorbidity, and whether they were followed up by a nurse, a urologist, or both.

For the current study, we used the following specific question on satisfaction with prostate cancer care as the outcome: "How satisfied are you as a prostate cancer patient with your health care?" The question was answered on a seven-point scale where 1 corresponded to "not satisfied at all" and 7 to "completely satisfied".

2.3. Data analysis

An analysis was performed to reveal any differences regarding satisfaction with care. The participants were divided into three groups based on who conducted the follow-ups: nurses, urologists, or a combination of both. The difference in patients' satisfaction after follow-ups by nurses, urologists, or the combination of both was further analyzed in subgroups based on patients' age (<65 or 65+ yr), level of education (low, middle, or high), self-reported comorbidity (Charlson comorbidity index = 0, 1, or 2+), treatment (AS, radical prostatectomy, or radiation), initial level of information (no/little or moderate/much), men's own experience of participation in the treatment decision (not at all/little or moderate/much), disease progression (defined as self-reported information on having received salvage radiotherapy or androgen deprivation therapy), and urinary bother according to EPIC-26 (no/little or moderate/much).

Likelihood ratio tests from ordinal regression were used to test the null hypothesis of similar satisfaction between groups. The analysis was performed using the free statistical software package R (GNU General Public License, www.r-project.org).

The study was approved by the Regional Ethics Board in Uppsala (reference number 2014/278).

3. Results

In total, 1288 of 1720 invited men (75%) answered the questionnaire. Out of these men, 1137 (88%) answered both the question on who performed the follow-up and the question regarding satisfaction with care. Of the 1137 men, 350 reported that they were followed up by nurses (31%), 598 (52%) by urologists, and 189 (17%) by both. The distribution between the three groups regarding age, level of education, initial level of information, and the men's own experience of participation in the treatment decision were similar. However, men in AS were more often followed up by urologists than by nurses (42% vs 25%), and men who had undergone radical prostatectomy were more often followed up by nurses than by urologists (61% vs 46%). Furthermore, men with Charlson comorbidity index = 0 were more often followed up by nurses than by both nurses and urologists (36% vs 26%; Table 1).

Table 1 – Baseline characteristics

	Nurse (n = 350)		Nurse and urologist (n = 189)		Urologist (n = 598)	
Age (yr), n (%)						
<65	235	(67)	120	(63)	387	(65)
65+	115	(33)	69	(37)	211	(35)
Level of education, n (%)						
Low	102	(29)	51	(27)	169	(28)
Intermediate	141	(40)	77	(41)	243	(41)
High	107	(31)	61	(32)	186	(31)
Charlson comorbidity index, n (%)						
0	127	(36)	50	(26)	187	(31)
1	115	(33)	66	(35)	207	(35)
2+	108	(31)	73	(39)	204	(34)
Treatment, n (%)						
Active surveillance	86	(25)	62	(33)	254	(42)
Radical prostatectomy	213	(61)	104	(55)	277	(46)
Radiation therapy	51	(15)	23	(12)	67	(11)
Information, n (%)						
No	11	(3)	2	(1)	8	(1)
Little	56	(16)	36	(19)	124	(21)
Moderate	179	(51)	97	(51)	265	(44)
Much	100	(29)	52	(28)	193	(32)
Missing	4	(1)	2	(1)	8	(1)
Participation, n (%)						
None	18	(5)	14	(7)	39	(7)
Little	19	(5)	11	(6)	57	(10)
Moderate	67	(19)	38	(20)	137	(23)
Much	243	(69)	124	(66)	356	(60)
Missing	3	(1)	2	(1)	9	(2)

Distribution of the participating patients was divided into subgroups based on follow-ups led by nurses, urologists, or the combination of both. The distribution is shown in percentage and actual number of participants (n).

3.1. *Perceived satisfaction with prostate cancer health care within the whole cohort*

Of the men followed up by nurses, 52% reported being completely satisfied with the care received (a score of 7 on the seven-point scale). Of men followed by urologists or the combination of nurses and urologists, 48% and 47%, respectively, reported being completely satisfied (Fig. 1). There was no statistically significant difference in satisfaction with health care between patients followed by nurses, urologists, or both.

3.2. *Estimated satisfaction based on patient's age and educational level*

There was no statistically significant difference in satisfaction with health care between follow-ups performed by nurses or urologists or by both, regardless of whether the patients were younger or older than 65 yr (Fig. 2A). Approximately 50% were completely satisfied with the care given by the nurse, urologist, or combination of both.

When dividing men based on the level of education, there was no significant difference in satisfaction regardless of who led the follow-up (Fig. 2B).

3.3. *Satisfaction based on comorbidity and treatment*

Comorbidity did not have an impact on the satisfaction, regardless of the level of comorbidity (Fig. 2C). Regarding treatment, there was no statistically significant difference in estimated satisfaction between follow-ups led by nurses or urologists, or by both (Fig. 2D).

A subgroup analysis of men who reported having received salvage radiotherapy or androgen deprivation therapy showed no statistically significant difference in satisfaction with health care between nurse- and urologist-led follow-ups (p = 0.28), neither did a subgroup analysis of men who reported moderate/much urinary bother according to EPIC-26 (p = 0.51).

3.4. *Impact of initial information and perceived participation in treatment decision on estimated satisfaction*

There was only a very small difference in estimated satisfaction between follow-ups by nurses or urologists, or by both,

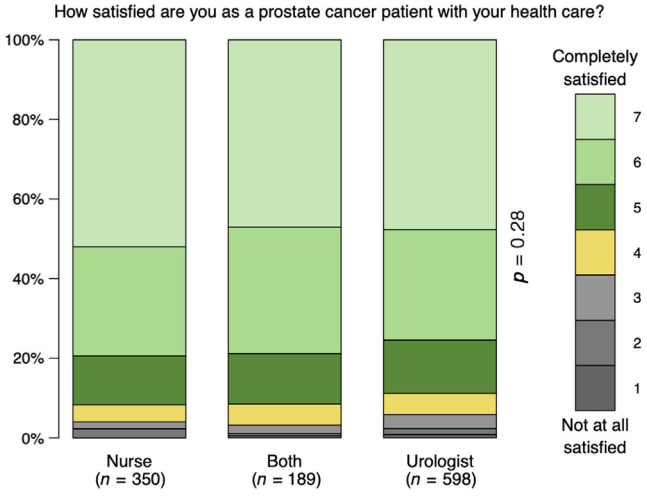

Fig. 1 – Self-rated satisfaction in the whole cohort without any subgroups and compared between follow-ups conducted by nurse, urologist, or the combination of both (n = 948).

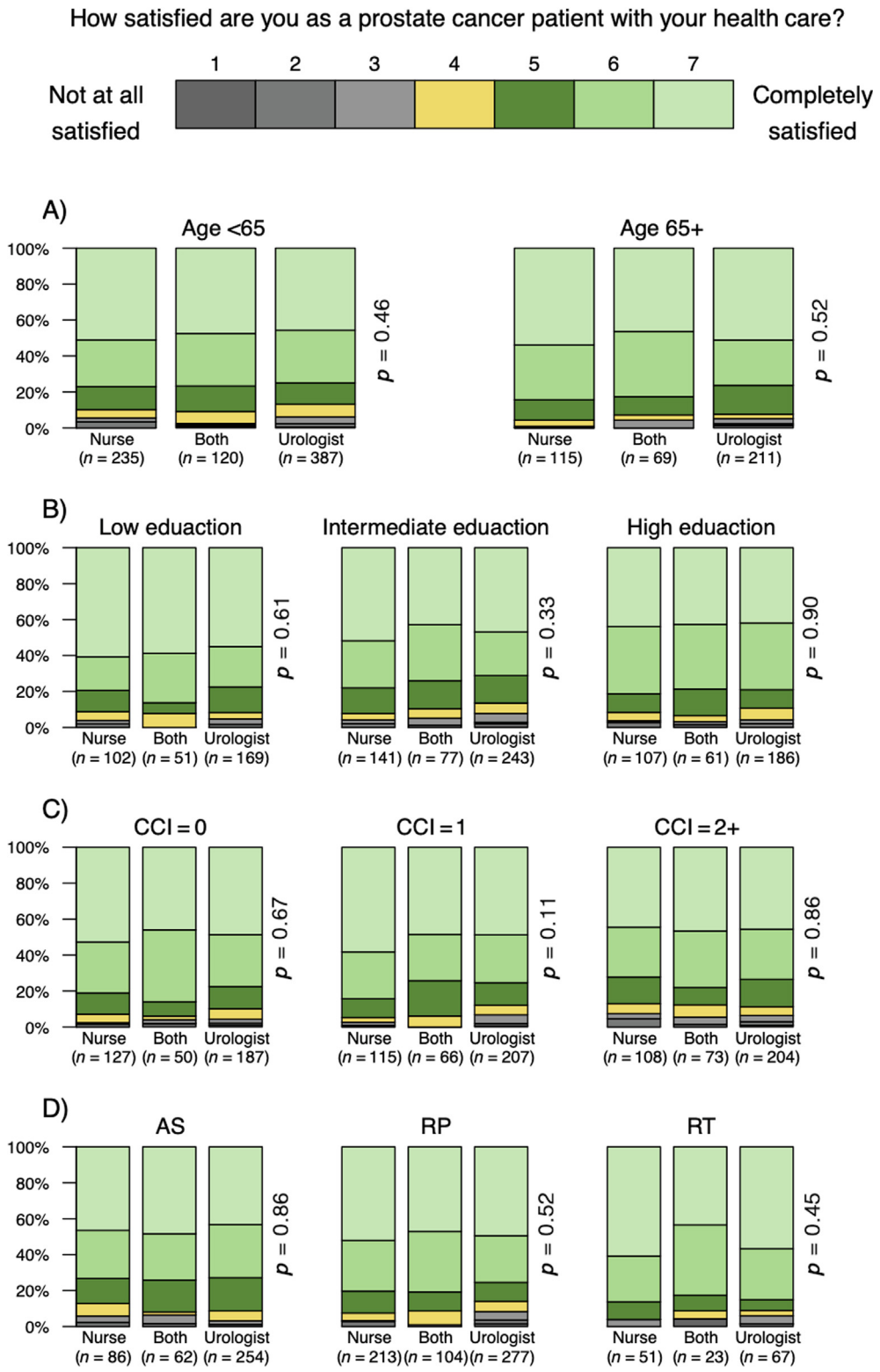

Fig. 2 – Self-rated satisfaction compared between follow-ups conducted by nurse, urologist, or the combination of both (*n* = 948). The patients are divided into subgroups based on (A) age, (B) level of education, (C) comorbidity, and (D) treatment. AS = active surveillance; CCI = Charlson comorbidity index; RP = radical prostatectomy; RT = radiotherapy.

depending on the level of information or perceived participation in treatment decision. Of 1123 patients, 237 (21%) reported receiving no or little information about prostate cancer. Among these men, <20% reported that they were completely satisfied with the follow-ups. In the group with moderate to much information, approximately 60% of patients were completely satisfied (Fig. 3A), but the estimated satisfaction was very similar regardless of who led the follow-ups. The majority of the men in this study perceived that they had been participating moderately or much

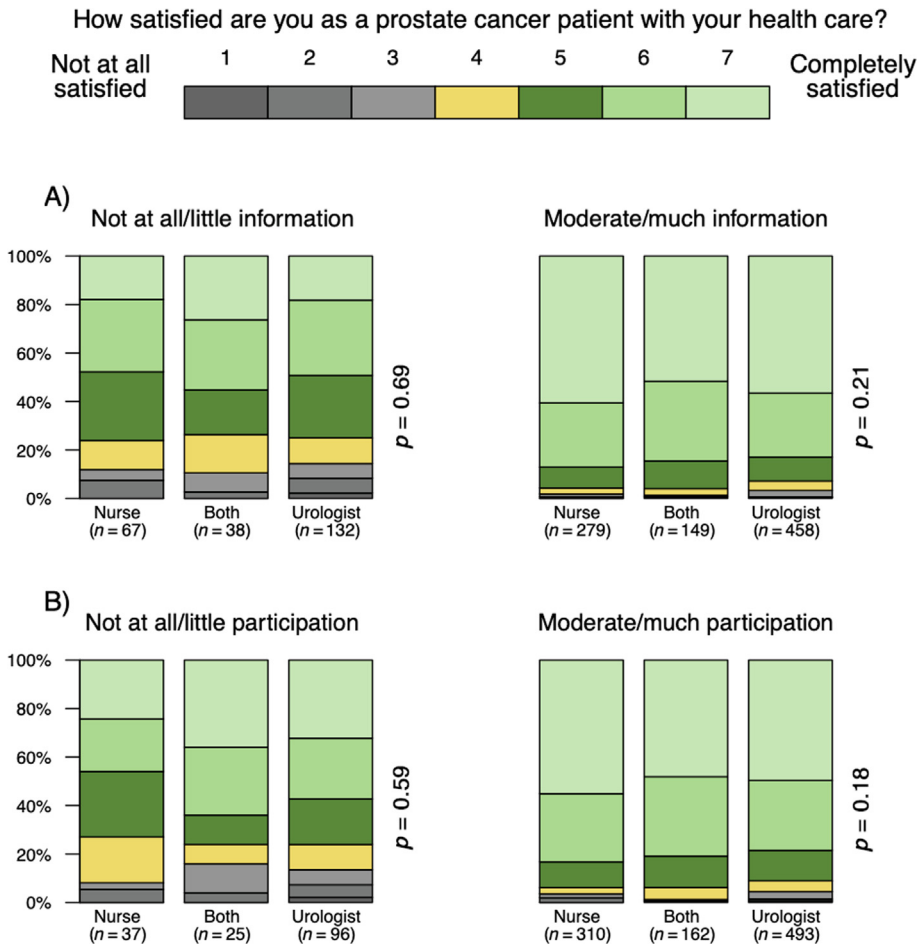

Fig. 3 – Self-rated satisfaction compared between follow-ups conducted by nurse, urologist, or the combination of both (n = 948). The patients are divided into subgroups based on (A) information about the illness and its course, and (B) participation in treatment decision.

in the treatment decision (965 of 1123 men [86%]; Fig. 3B), and >50% were completely satisfied with the care given regardless of whether the follow-ups were led by a nurse, a urologist, or a combination of both.

4. Discussion

We found that every second man was followed up by a urologist only and every third man by a nurse only. The overall satisfaction with health care was high, regardless of who performed the follow-up and regardless of age, level of education, comorbidity, cancer treatment, disease progression, urinary bother, given information, or participation in treatment decision.

With the increasing number of men who are diagnosed with prostate cancer [5], it is important to reduce the health care burden without decreasing the patient's perceived satisfaction and safety. We have previously shown that there is no overall difference in satisfaction between follow-ups led by nurses, urologists, or the combination of both in this population-based cohort [3]. Nurse-led follow-up is part of the Swedish national guidelines [1] where nurses with training in prostate cancer management follow men in AS or after curative treatment according to detailed national guidelines and consult a specialist physician if signs of disease progression are present. We found that only 60% of men who had undergone radical prostatectomy had nurse-led follow-up, suggesting that the implementation could increase to ascertain maximization of the health care resources. Leahy and colleagues [6] showed in a randomized study that nurse-led telephone consultation was as satisfying for the patients as face to face consultation with an oncologist. However, in our study, we have no information regarding whether the follow-up was by telephone or face to face.

It was more common among men in AS to see a urologist than a nurse. This could be explained by the lack of consensus on how to follow up and when to treat men in AS. However, we previously found that men who were assigned a named nurse navigator reported higher satisfaction of prostate cancer care [3]. In the ProtecT trial, nurse-led AS clinics were investigated on how the participants perceived the nurse-led follow-up. The trial found that patients valued the flexibility, accessibility, and continuity with nurse-led follow-up [2]. Previous studies have pointed out that the nurse responsible for such a function should have a close collaboration and good communication with the urologist and clear evidence-based guidelines for dealing with the patient, to ensure correct information and sustained patient safety [7,8].

We hypothesized that there could be a group of patients for whom nurse-led follow-ups would result in less satisfaction with health care. However, in the present study, we found no indication that age, level of education, comorbidity, treatment received, disease progression, or urinary bother affected the self-reported satisfaction with the health care, regardless of who performed the follow-up. None of these factors affected the level of satisfaction when comparing follow-ups led by a nurse, a urologist, or a combination of both. This suggests that there are no easily identifiable demographic factors that hamper nurse-led follow-ups.

Our study shows that prostate cancer patients are highly satisfied with their health care in regard to the information received and their perceived participation in treatment decision-making. However, there is still a need for further improvements regarding information about diagnosis and treatment for men with low-risk prostate cancer, especially information and knowledge about side effects [9,10]. A study by Tarrant and colleagues [11] shows that men with prostate cancer seeing a specialist nurse were significantly more satisfied with the information given about results, choices of treatment, and what other supportive functions were available, than patients without access to a specialist nurse. There was no statistically significant difference between seeing a nurse or a physician with regard to discussions about side effects or why certain treatments were not an option for that specific man [11]. This implicates that information is important, but it is not crucial who gives the information—a nurse or a urologist.

Several studies show that nurse-navigated receptions render high level of satisfaction, possibility of easily contacting health care, as well as sustained level of patient safety [2,11–15]. In addition, the follow-through is more efficient and makes room for shorter queues for visiting urologists. De Leeuw and Larsson [7] have pointed out that there are nurse-navigated receptions in many areas within cancer health care with high-quality care that are both safe and efficient for the patient. In a study in the UK, with focus on nurse-led follow-up of prostate cancer patients in AS, men scored very high satisfaction with care given and also showed high confidence in the nurse's competence and the information they received from the nurse [16]. The Swedish national guidelines promote nurse-led follow-ups of men with low-risk prostate cancer [1], but could be even more specified to ensure the safety of the patient.

4.1. Strengths and limitations

The high response rate (75%, n = 1288) is a strength of this population-based study. The results are based on original data where a single question about satisfaction was answered on a seven-digit ordinal scale. The seven-digit scale gave the opportunity for a nuanced answer, and the uneven number gives the respondent the possibility of being neutral or ambivalent [17]. There is a risk of a recall bias as 7 yr have passed from when the men were diagnosed until answering the questionnaire, especially regarding information given at the time of diagnosis and participation in treatment decision. The level of satisfaction can also be influenced by incidents during follow-up. Treatment strategies have changed during this time and should be taken into consideration when interpreting and comparing our results in the context of today's practice. AS is now a well-established choice for men with low-risk prostate cancer and an magnetic resonance imaging scan of the prostate is often performed. Therefore, the overall satisfaction of the prostate cancer care given today might be higher.

5. Conclusions

Our study shows that men with low-risk prostate cancer are mostly followed up by urologists. The estimated high level of satisfaction is maintained regardless of who performs the follow-ups and regardless of the men's age, level of education, comorbidity, disease progression, urinary bother, given information, participation in the decision of treatment, and the treatment itself. Our study suggests that men with prostate cancer can in the future be offered nurse-led follow-up on a more regular basis and still maintain their satisfaction with health care.

***Author contributions*:** Oskar Bergengren had full access to all the data in the study and takes responsibility for the integrity of the data and the accuracy of the data analysis.
***Study concept and design*:** Bergengren, Kaihola, Borgefeldt, Johansson, Garmo, Bill-Axelson.
***Acquisition of data*:** Bergengren, Johansson, Bill-Axelson.
***Analysis and interpretation of data*:** Bergengren, Kaihola, Borgefeldt, Johansson, Garmo, Bill-Axelson.
***Drafting of the manuscript*:** Bergengren, Kaihola.
***Critical revision of the manuscript for important intellectual content*:** Bergengren, Kaihola, Borgefeldt, Johansson, Garmo, Bill-Axelson.
***Statistical analysis*:** Garmo.
***Obtaining funding*:** Bill-Axelson.
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***Supervision*:** Bill-Axelson.
***Other*:** None.

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