



Gynecological cancer alarm symptoms in the general population – Prevalences, contacts to specialist and diagnoses

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English resumé Background

Early diagnosis and fast treatment are considered of essential importance for the prognosis in most cancer forms. This also applies to gynecological cancer diseases. To promote fast and efficient diagnosis and treatment several initiatives such as specialised investigative programmes have been implemented. Many of these initiatives are based on a number of symptoms that have been shown to be associated with gynecological cancer. Most of the current knowledge about these symptoms is derived from cancer patients from a secondary care setting, where studies may be flawed by recall bias. This means that the predictive values of the symptoms for later cancer diseases are uncertain. Furthermore, studies have shown that low socioeconomic status (SES) and lifestyle are associated with delayed diagnosis and poorer survival among gynecological cancer patients. The current guidelines do, however, not take SES and lifestyle into account, and whether the investigations of the symptoms are influenced by these factors is yet unknown. Efficient investigation is essential when cancer is suspected, but our current knowledge about cancer symptoms in the general population level. Thus it is crucial to collect information on the prevalence of the symptoms in the general population, including which investigative courses the symptoms lead to. Finally, the prognostic values of the symptoms in the general population also have an impact on the organisation of cancer investigation and for the communication with patients.

Aims:

The overall purpose of the project was to investigate the prevalence of a number of gynecological cancer alarm symptoms, factors of importance for investigation of these symptoms and the prognostic value of the symptoms in the Danish population.

The aims of each of the separate studies were:

Study 1:

I) To describe the prevalence of gynecological cancer alarm symptoms in different age groups in the Danish population.

II) To investigate whether the symptoms are reported as single symptoms, or if multiple symptoms are reported at the same time by women in different age groups.

Study 2:

To investigate how contact with specialist care is associated with lifestyle factors or socioeconomic status among women reporting gynecological cancer alarm symptoms.

Study 3:

To investigate the significance of newly onset gynecological cancer alarm symptoms for the development of gynecological cancer and premalignant conditions in the Danish population.





Methods:

The study was a nationwide cohort study based on an electronic questionnaire and register data. A total of 100 000 Danish citizens aged 20 or more were randomly selected from the Danish Civil Registration System (CRS) and invited to participate in a survey concerning symptom experiences and healthcare seeking in the general population.

The questionnaire was designed to elucidate the prevalence of a number of symptoms experienced within a four-week time period and the individuals' reaction to symptoms, including healthcare-seeking behaviour. The symptoms of interest for the study were collected from national and international guidelines regarding a number of cancer diseases and complemented with frequent and commonly occurring symptoms. Additionally the questionnaire contained a number of questions regarding lifestyle (smoking, alcohol consumption, height, weight). For this thesis we selected four specific and 14 unspecific alarm symptoms from guidelines on diagnosis of cervical cancer, endometrial cancer and ovarian cancer. In Study 1 all symptom experiences were included in the analyses. In Study 2 only the four specific alarm symptoms were included, whereas Study 3 included all symptom experiences. For both Studies 2 and 3 only symptoms with an onset less than six months ago were included.

Based on the Danish Civil Registration System (CRS), information about each participant was collected from Statistics Denmark regarding educational level, labour market affiliation, marital status, ethnicity and household income at the time of completion of the questionnaire.

From the National Patient Register information about contacts to gynecologists was obtained for all participants. Furthermore, data on whether the participants had been diagnosed with gynecological cancer or premalignant condition in the year following symptom-reporting were collected.

Results:

Of the 100 000 invited individuals 51 090 were women. Of these 2484 were not able to participate due to language problems, illness, unknown address or because they were dead. Of the remaining, 26 466 participated in the survey, yielding a response rate of 54.5%.

We found a great variation in symptom-reporting in the population. The most frequently reported symptoms were tiredness (reported by 53%) and bloating (37%), while involuntary weight loss (3%) and postmenopausal bleeding (2%) were the least reported symptoms. Most of the symptoms were more common among younger women, who also more frequently reported multiple symptoms simultaneously. Regarding the four specific symptoms (pelvic pain, postmenopausal bleeding, pain during intercourse and bleeding after intercourse), the proportion of individuals who had contact with a gynecologist varied between 12.9% for postmenopausal bleeding and 23.9% for pelvic pain. We found that a higher level of education was associated with increased odds of being seen by a gynecologist (OR 2.3; 95% CI 1.2-4.5). The same was the case for former smoking (OR 2.2; 95% CI 1.38-3.53). Inversely, a moderate intake of alcohol was associated with lower odds of being seen by a gynecologist (OR 0.64; 95% CI 0.41-0.98).

Among 13 954 women with newly onset gynecological symptoms 52 new cases of gynecological cancer or premalignant conditions were diagnosed. The PPV for being diagnosed with a gynecological cancer or premalignant condition was 0.2% after reporting at least one of the 18 symptoms. The PPV rose to 0.4%, if the woman had contacted her GP regarding at least one of the four specific symptoms.

Among those diagnosed with cancer 7.1% had reported at least one of the four specific alarm symptoms. Some 32.1% had reported at least one of the 14 unspecific symptoms, and 60.7% of those diagnosed with cancer had not reported any of the 18 symptoms.

Conclusion:

We found that numerous symptoms mentioned in guidelines regarding gynecological cancer are frequent in the population. The symptoms occurred more often among younger women, who also reported multiple symptoms at the same time, whereas older women more often reported single symptoms.

The proportion of women investigated by a gynecologist for newly onset specific gynecological cancer alarm symptoms was highest among women with a high level of education and former smokers, and lowest among women with a moderate intake of alcohol.

The predictive values of single symptoms in the general population are very low. Almost half of the women with gynecological cancer or premalignant condition only reported unspecific symptoms prior to the diagnosis, and almost one third did not report any of the 18 symptoms. Implications:





Since the predictive values of the symptoms are very low and a considerable proportion of patients with cancer and premalignant conditions do not report classical symptoms, other options for early cancer diagnosis must be explored. We have also shown a social disparity in the diagnosis, and the causes for this should be explored in future studies. A better understanding of these factors may be the first step towards reducing inequality in healthcare.

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