Factors associated with non-participation in cervical cancer screening – A nationwide study of nearly half a million women in Denmark

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ABSTRACT

Cervical cancer occurs most often in under-screened women. In this nationwide register study, we described differences in sociodemographic characteristics between passive and active non-participants and examined socio-demographic characteristics, reproductive history, and mental and physical health as potential determinants for passive non-participation compared with participation in the Danish cervical cancer screening program. Screening history in women aged 23–49 years invited for cervical cancer screening in 2008–2009 was retrieved from the Danish Pathology Databank with information about dates of invitation and unsubscription. We identified participants ($n = 402,984$), active non-participants ($n = 10,251$) and passive non-participants ($n = 63,435$) within four years following baseline invitation and retrieved data about the study population from high-quality registries. We examined differences in socio-demographic characteristics of passive and active non-participants, and used multiple logistic regression analyses to identify potential determinants of passive non-participation. We found that active and passive non-participants differed in relation to socio-demography. When compared with screening participants, the odds of passive non-participation was increased in women who originated from less developed countries; were unmarried; had basic education or low income; had four or more children; smoked during pregnancy; had multiple induced abortions; or had a history of obesity, intoxicant abuse or schizophrenia or other psychoses. In conclusion, in this nationwide, prospective, population-based study, differences in socio-demographic characteristics between passive and active non-participants were found. Furthermore, sociodemography, reproductive history, and mental and physical health were determinants for passive non-participation. Addressing inequalities in screening attendance may help to further decrease the incidence of and mortality from cervical cancer.

1. Introduction

Before cervical cancer screening was introduced in Denmark in the 1960s, the incidence of this disease was 30 cases per 100,000 women per year (Engholm et al., 2016). Since then, free of charge cervical cancer screening has gradually been implemented, and by the mid-1990s all Danish counties had implemented some organized screening (Lynge et al., 2017). As a result of this initiative, the cervical cancer incidence had decreased to 12/100.000 by the mid-1990s (Baldur-Felskov et al., 2015). However, since then the incidence has remained stable and is still higher than in other Nordic and several European countries (Elfstrom et al., 2015). High attendance in organized cervical cancer screening is crucial for an effective program (Lynge et al., 2017).

In 2016, the coverage of cervical cancer screening in Denmark was 74% (Danish Quality Database for Cervical Cancer Screening, 2017). Among women diagnosed with cervical cancer, almost half have a deficient screening history before the cancer diagnosis (Kirschner et al., 2011).

Several studies have investigated predictors for non-participation in cervical cancer screening, including socio-demographic factors (Eaker et al., 2001; Rodvall et al., 2005; Lopez-de-Andres et al., 2010; Hansen et al., 2011; Walsh et al., 2011; Schoueri-Mychasiw and McDonald, 2013; Bussiere et al., 2014; Kristensson et al., 2014; Virtanen et al., 2015; Leinonen et al., 2017a; Sabates and Feinstein, 2006), reproductive history (Eaker et al., 2001; Hansen et al., 2011; Leinonen et al., 2017a; Sabates and Feinstein, 2006), and mental (Aggarwal et al., 2013; Richard et al., 2015) and physical health (Lopez-de-Andres et al.,

2010; Bussiere et al., 2014; Leinonen et al., 2017a; Richard et al., 2015; Cohen et al., 2008; Maruthur et al., 2009). Many studies were, however, cross-sectional (Lopez-de-Andres et al., 2010; Schoueri-Mychasiw and McDonald, 2013; Bussiere et al., 2014; Sabates and Feinstein, 2006; Richard et al., 2015) and based on self-reported data (Eaker et al., 2001; Lopez-de-Andres et al., 2010; Hansen et al., 2011; Schoueri-Mychasiw and McDonald, 2013; Bussiere et al., 2014; Sabates and Feinstein, 2006; Richard et al., 2015). In addition, non-participants have mostly been investigated as one group combining active non-participants (invited women who actively decline attendance) and passive non-participants (invited women who fail to participate without actively declining), and this may be too simplistic. A study of breast cancer screening found that passive non-participants were more socially deprived than active non-participants (L.F. Jensen et al., 2012). In the Danish organized cervical cancer screening program, women can also actively unsubscribe (Danish National Board of Health, 2012), and it is possible that differences exist between active and passive non-participants. If so, characteristics of non-participants should be studied separately for each group. Such information could improve our understanding of mechanisms related to non-participation and guide development of group-specific interventions to increase screening coverage.

In this nationwide register-based cohort study, we described non-participants in the Danish cervical cancer screening program, including potential differences in socio-demographic characteristics between active and passive non-participants. Furthermore, we assessed the role of socio-demographic factors, reproductive history, and mental and physical health for passive non-participation in cervical cancer screening in Denmark.

2. Material and methods

2.1. Organization of cervical cancer screening in Denmark

In Denmark, the responsibility for cervical cancer screening lies with the country's five administrative regions who are in charge of implementing the nationwide screening guidelines issued by the National Board of Health. In the current guidelines from 2012, screening is recommended every three years for women aged 23–49 years and every five years for those aged 50–64 (Danish National Board of Health, 2012). A nationwide database, the Pathology Data-bank, serves as the administrative system for the screening program. The Pathology Databank contains information about dates of all screening invitations and reminders, as well as dates and results of all cervical cytologies (from both organized and opportunistic screening) and all histologies performed in the country. Furthermore, the database contains information on active unsubscription from cervical cancer screening (Erichsen et al., 2010). Women can unsubscribe from the program via an online link provided in the invitation letter or by calling the regional screening secretariat.

If a woman in the screening age group does not have a smear registered in the Pathology Databank within the recommended screening interval, and she has not actively unsubscribed from screening, she will receive an invitation for organized cervical cancer screening. If no smear (or unsubscription from screening) is registered within three months after the invitation, a first reminder is sent. Subsequently, if three more months pass with no activity, the woman receives a second reminder. In case of no response to any of these letters, the woman is re-invited for screening when the recommended screening interval for her age group has elapsed (Danish National Board of Health, 2012).

2.2. Data sources

All residents in Denmark are recorded in the computerized Civil Registration System with a unique personal identification number (PIN). The PIN contains information on age and sex and is assigned to all residents at birth or immigration into the country. The PIN is used as a personal identifier in all national registries and thus provides a unique possibility for accurate registry linkage (Pedersen, 2011).

In the present study, we used the PIN to link information from several nationwide registries: The *Pathology Databank* which is described above (Erichsen et al., 2010); the *National Patient Register*, which contains information on hospital admissions since 1977 and outpatient hospital contacts since 1995 (Lynge et al., 2011); the *Cancer Register*, including information on all cancer diagnoses since 1943 (Gjerstorff, 2011); the *Medical Birth Register,* containing information on livebirths, stillbirths and pregnancy-related variables since 1973 (Knudsen and Olsen, 1998); the *Prescription Register*, holding information on prescriptions redeemed at outpatient pharmacies since 1995 (Kildemoes et al., 2011); the *Psychiatric Central Research Register*, containing information on psychiatric admissions since 1969 and psychiatric outpatient contacts since 1995 (Mors et al., 2011); and *databases in Statistics Denmark*, including information on socio-demographic measures (Statistics Denmark).

2.3. Study population and definition of active and passive non-participation

In the Pathology Databank, we identified all 23–49-year-old women invited for routine cervical cancer screening (baseline invitation) in 2008–2009 ($n = 543,325$). A follow-up period of four years was chosen to allow for some delay in participation. We excluded women with incomplete information on socio-demographic measures ($n = 45,846$); women with a total hysterectomy registered in the National Patient Registry before baseline or during follow-up ($n = 9642$); and women who emigrated or died during follow-up ($n = 2251$). Furthermore, to ensure that all women included in analysis had been reminded and re-invited for screening in accordance with the recommended invitation procedure, we excluded women with missing information on reminder letters or second invitation following baseline invitation ($n = 8916$). This resulted in a study population of 476,670 women. Women with a cervical cytology registered in the Pathology Databank within the 4-year follow-up period were considered screening participants ($n = 402,984$). Women who actively unsubscribed during follow-up were considered active non-participants ($n = 10,251$). Women who were neither screening participants nor active non-participants were considered passive non-participants ($n = 63,435$).

2.4. Explanatory variables

We a priori selected four categories of covariates potentially influencing screening participation: Socio-demographic characteristics, reproductive history, mental health, and physical health.

Socio-demographic characteristics included age, country of origin, marital status, highest attained educational level, and income (retrieved from Statistics Denmark). With respect to reproductive history, we considered number of induced abortions (registered in the National Patient Register), and number of live born children and smoking during last pregnancy (measured in the Medical Birth Register). Mental health included history of intoxicant abuse, schizophrenia and other psychoses, affective disorders, anxiety, adjustment and obsessive compulsive disorder (OCD), and eating disorders (registered in the Psychiatric Central Research Register). In relation to physical health, we defined a measure of obesity based on a combination of obesity diagnoses in the National Patient Register and prescription medicine for decreasing body weight in the Prescription Register. Furthermore, we obtained information on previous cancer diagnoses from the Cancer Registry and information about previous participation in cervical cancer screening and history of cervical abnormalities from the Pathology Databank. Lastly, we calculated a cumulative score for comorbidity, the Charlson Comorbidity Index (Charlson et al., 1987), based on diagnoses in the National Patient Register from the start of the register in 1977 to date of invitation. All variable definitions are further specified in Supplemental Table S1. Socio-demographic characteristics were measured in the year