Hydatidiform mole: Accuracy of the Danish National Patient Registry, the Danish Cancer Registry, and the Danish Pathology Registry 1999-2010

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Abstract

Objectives
We investigated the accuracy of registration of hydatidiform mole (HM) in the Danish National Patient Registry (NPR), the Danish Cancer Registry (DCR) and the Danish Pathology Registry (DPR). In NPR, data are registered whenever a patient is discharged from a hospital or an outpatient clinic. DCR register first-time diagnoses of cancer and related diseases like HM. Before 1 January 2004, data were reported to DCR by the responsible clinician, and since 2004 most data are imported to DCR from other registries. Registration in DPR is linked to the computerized writing of pathology reports.

Methods
We selected women registered with a first-time diagnosis of HM in NPR, DCR, and DPR. Using the most complete registry as the reference standard, we calculated the completeness and the positive predictive value (PPV) of women registered with a HM in the other registries. The agreement and kappa values between morphological subdiagnoses (complete and partial HM) were calculated.

Results
In NPR and/or DPR, 1637 women were identified: 1123 (69%) were found in both registries, 72 (4%) only in NPR, and 442 (27%) only in DPR. In DCR and/or DPR, 1498 women were identified: 1173 (78%) in both registries, 47 (3%) only in DCR, and 278 (19%) only in DPR. Thus, DPR was the most complete registry. For 1999-2010, completeness of NPR compared to DPR was 72%, PPV was 94%. For 1999-2003, completeness of DCR compared to DPR was 72%, increasing to 90% after 2003; PPV was 96% throughout the period. For 1999-2010, agreement between morphological subdiagnoses in NPR and DPR was 84% (kappa: 0.68). For 1999-2003, agreement between morphological subdiagnoses in DCR and DPR was 71% (kappa: 0.45), increasing to 77% (kappa: 0.54) after 2003.

Conclusions
DPR was the most complete registry. However, the completeness and PPV were also high in both NPR and DCR. The agreement and kappa values between morphological subdiagnoses in NPR and DPR, and for DCR and DPR were moderate to good. For DCR, the completeness and agreement between morphological subdiagnoses were higher after 2003, possible explained by the introduction of import of data from other registries in 2004.