The Swedish Maternal Health Care Register: Internal Validity, User Perspectives and Register Outcomes; and Experiences by Midwives in Antenatal Care

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Akademisk avhandling

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Abstract

Background Established in 1999, the Swedish Maternal Health Care Register (MHCR), collects data on pregnant women and their offspring. Since 2013, the MHCR has been a part of the Swedish Pregnancy Register (SPR). Data are entered manually into the MHCR by midwives in antenatal care (ANC). ANC is primarily organised within public primary health care in Sweden. Midwives are the primary providers of health care during pregnancy, and they are responsible for providing information about prenatal diagnosis to expecting parents.

Aims This thesis investigated internal validity of MHCR data, and user’s experiences of the MHCR. Prenatal diagnosis was explored in regard to local guidelines and to background characteristics and pregnancy outcomes. Factors affecting the work situation for midwives in ANC, as well as their experiences on informing expecting parents about prenatal diagnosis were investigated.

Methods Study I, II and III were cross-sectional studies. Study I included data from MHCR and medical records on 878 pregnancies during 2011. Study III analysed data from MHCR/SPR, in total 284,789 pregnancies for 2011 to 2013. Study II was a questionnaire study with a quantitative and a qualitative component, including 989 participants. Study IV was a qualitative study applying qualitative content analysis. Fifteen midwives participated in individual, telephone interviews.

Main findings Overall, the degree of coverage of variables was high in the MHCR as well as in the medical records. For 17 of the 27 variables, agreement of data in both data sources reached 95% or more. Possible systematic errors were identified for two variables (Paper I). Midwives valued MHCR generally positively, although manual registration of data into the MHCR was perceived burdensome. Foremost midwives engaged in supervision regularly accessed data on pregnant women at their own ANC clinic (Paper II). Offers on prenatal diagnosis varied considerably between the 21 Swedish counties during 2011 to 2013. Maternal age and educational level demonstrated strong associations with uptake of prenatal diagnosis (Paper III). Midwives in ANC reported their work load as manageable. Clinical guidelines, continuing education, and collaboration in the chain of care of pregnant women, were supportive factors for midwives work situation in antenatal care. Administrative work load was perceived as strenuous and informing expecting parents about prenatal diagnosis was challenging (Paper IV).

Conclusions Data in the MHCR demonstrated sufficient internal validity. MHCR was an underutilised source in operational planning of ANC. Offers and uptake on prenatal diagnosis was unequally distributed in Sweden. Midwives enjoyed their work in ANC. Administrative work was strenuous and informing expecting parents about prenatal diagnosis was challenging. The register can further develop its report systems to be used in a higher extent in evaluation and planning of Swedish maternal health care services. Expecting couples in Sweden should be offered the same opportunities on prenatal diagnosis. Pedagogical tools may facilitate midwives mission to inform expecting parents with varying pre-understanding about prenatal diagnosis.

Key words quality registers, medical records, validity, degree of coverage, antenatal care, pregnancy, prenatal diagnosis, uptake, work condition, guidelines, epidemiology, qualitative research