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COHERENT MONITORING AND FOLLOW-UP OF PREGNANT WOMEN WITH A HEART DISEASE

A health technology assessment - summary

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Summary

Heart diseases are today the second most frequent cause of dead following pregnancy and birth. Pregnant women with heart disease is a growing patient group in Denmark and it is assessed that 0.8% of all newborn, i.e. 500, have a congenital heart disease. Besides this a group of women will in their childhood and adolescence have a heart disease. Due to these reasons an increasing number of young women with heart disease will grow up and have a wish to start a family and have a pregnancy. Pregnancy and birth can for these women with certain forms of congenital heart diseases be life-threatening for the woman and the foetus.

It is assessed that there is annually around 400 women with heart disease in Denmark, who are pregnant. A number which is expected to increase to around 1,000 women during the next 10-20 years. Besides this the complexity of the heart diseases will be enlarged in the coming years, because more women with complex and serious heart diseases now to a larger extent will survive and become adult. There have in Denmark been a number of cases of maternal death among pregnant women with heart disease in the recent years, why the attention of this group of pregnant women should be closer with the aim to influence this development and to help the patients.

The effort and offers regarding monitoring and follow-up of pregnant women with a heart disease have previously been more divided in between the primary and secondary health care sector (hospitals), as well as between the clinics and departments within the hospitals. Copenhagen University Hospital (Rigshospitalet) have since October 2003 established a virtual centre for pregnant women with a heart disease, where the departments of cardiology, obstetrics and anaesthesiology have worked closely together to help women with heart disease in their pregnancy. The aim of the centre is that the pregnant women are offered an integrated monitoring and follow-up both before, during and after the pregnancy and birth to be able to have as much as possible an uncomplicated pregnancy and to minimize the health risks of the women and the foetus. Pregnant women with heart disease is referred to the centre by the general practitioner, specialist or from a hospital department. The patient group in focus is patients from the eastern part of Denmark. The centre has an activity of 150 patients per year.

Purpose

In order to provide Danish decision-makers with essential information on the consequences of an appropriate distribution of assignments and coordination between sectors and personnel concerning offers to pregnant women with a heart disease, the purpose of this project is to carry out a Health Technology Assessment of "The centre for pregnant women with a heart disease" at Copenhagen University Hospital in Denmark. The activity at the centre will be compared with the up till now divided activity and effort towards the target group in between sectors. The health technology assessment will focus on the consequences for the woman and the foetus, consequences for the organisation and the personnel, as well as the economic consequences of centre and its activity.

Methods

In the present health technology assessment it was not possible, nor defensible, to randomise patients to receive either coherent monitoring and follow-up at "The Centre for pregnant women with a heart disease" or the traditional practice for monitoring and follow-up as a control group. One reason is that it has been found unethical with a randomized study, because the patients are pregnant with a heart disease, which need monitoring and follow-up by specialists. Secondly, it was for practical reasons not possible to conduct a prospective data collection of the period before the establishment of the centre in 2003.

Summary in: Sundhedsstyrelsen, Center for Evaluering og Medicinsk Teknologivurdering. Sammenhængende monitorering og opfølgning af gravide med hjertesygdom – En medicinsk Teknologivurdering. Medicinsk Teknologivurdering 2006; 6(11). København: Sundhedsstyrelsen, Center for Evaluering og Medicinsk Teknologivurdering, 2006. p 11-15. Full length pdf at www.cemtv.dk

The health technology assessment project is instead designed as a quasi-experimental "before and after" study comparing a prospective cohort of patients in the centre with a comparable historic cohort of pregnant women with heart disease.

Below the different methods used for data collection and analysis in the health technology assessment are summarized.

Part of the health technology assessment	Methods	Sample and number
Technology	*Systematic review of medical records* *Clinical database*	Pregnant women with heart disease. 56 women from the period before the centre (historical cohort) and 50 women from the period after the establishment of the centre
	Description of patient flow (case description)	Pregnant women with heart disease. 7 cases
Organisation	*Description of the organisation and analysis*	Desk research using existing material
	Semi-structured interviews	Interviews with personnel in the Centre for pregnant women with a heart disease (specialists, midwifes, and nurses)
Patient	*Structured interviews*	5 previously pregnant women with a heart disease. 3 persons from the period before the centre and 3 persons from the period after establishment of the centre. One person covered both periods.
Economy	*Cost analysis and assessment of socioeconomic consequences*	Data from the three other parts of the health technology assessment, charges.

Results

Below the main results and conclusions from each part of the health technology assessment (Technology, Organisation, Patient and Economy) are summarized.

Technology

The patients selected to represent the period before the establishment of the centre (historical control) was comparable with the patients included in the study from the period after the establishment of the centre. This was based on a number of parameters such as status of occupational employment, absence from work, risk of maternal cardiovascular events, as well as neonatal events.

The health technology assessment shows that a change in health status of the children was found after the establishment of the centre. The body weight of the children born is significantly higher in the period after the establishment of the centre than before, and this without any differences in the average gestational age at birth. Similarly is the number of neonatal events significantly lower in the period after the establishment of the centre than before. This is especially the case with respect to fewer premature births experienced and fewer cases of children with a low birth weight compared with the gestation age. Finally, the children born in the period after the establishment of the centre have an improved pH value of the umbilical cord than children born before the establishment of the centre. Overall it can be concluded that the health status of the newborn children have been improved with the establishment of "The Centre for pregnant women with a heart disease".

With the centre more women than before have got a plan for their delivery and significantly more women have a plan for anaesthesia during delivery.

With respect to the delivery there are significantly fewer women in the period after the establishment of the centre, who experience a spontaneous delivery. A higher number of deliveries are started and a higher number of women are having caesarean section in the period after. One potential explanation for the increase in deliveries started is that a larger share of women in the period after lives a long way from Copenhagen University Hospital, and that delivery at the local hospital in these cases are avoided starting the delivery. The increase in the number of caesarean sections in the period after reflects partly a general trend in Denmark in the period 2000-2004 and partly some direct effects from the establishment of the centre with the increased focus upon the patients' heart

diseases. The clinical database and the collection of data from larger patient samples must in the future investigate, whether this is actually the case.

The data material does, however, not show any significant differences in the health status of the women or the development of heart diseases after the establishment of the centre.

In the period before the establishment of the centre there is a higher number of outpatient visits at the outpatient clinic for obstetrics and cardiology. In the period after the establishment of the centre these outpatient visits are instead at "The Centre for pregnant women with a heart disease". Corresponding there is on average less hospitalization at the departments of obstetric and cardiology at Copenhagen University Hospital in the period after compared with before although this difference is not significant. These differences indicate that there have been improvements regarding the use of the available resources for the health care sector and patients in the period after the establishment of the centre.

Organisation

The establishment of "The Centre for pregnant women with a heart disease" has had a number of consequences both for the patient and the personnel. Among these is the change in the organisation that the centre has implied.

The structure with the shared activities between the department of obstetrics (The Juliane Marie Centre at Copenhagen University Hospital) and the department of cardiology (Heart Centre at Copenhagen University Hospital) requires a special organisation. This is taken care of by a steering committee composed of the management from both departments. In the long run it is important that the steering committees effort towards the centre is prioritized to provide focus upon the future strategic development of the centre.

The management of the centre is taken care of by the team manager. This person has no managerial competence towards the personnel, which makes the structure vulnerable to the goodwill and planning in the two departments, where the personnel in the centre comes from. To change this a specialist needs to be appointed with the main task of running the centre. The management of and the activities in "The Centre for pregnant women with a heart disease" does not require a fulltime position, why the specialist appointed should either be part of the department of cardiology or the department of obstetrics for the rest of the working time.

The monthly conference with the participation of all the involved persons in the centre is a central organisational element in the structure and construction of the centre. This conference links the effort towards the patients together and constitutes the frame for the practical planning of the activities of the centre. The conference has been very well functioning and is of central importance for the centre in the future.

The structure and construction with a shared patient consultation in the outpatient clinic every Friday morning is a cornerstone in the centre's philosophy. The patients are offered a coordinated and well planned patient flow with a minimized risk of having different and conflicting information. The specialists offer an improved shared consultation, which constitute the future treatment and shared information to the patients.

The shared care of the patients imply a high degree of development of competences among the personnel in the centre, as they obtain an insight in the different specialty areas. This implies that the personnel in the future can offer a more qualified counselling of the pregnant women with heart diseases.

"The Centre for pregnant women with a heart disease" has existed in 1½ year. This is normally seen as a rather short period to obtain the organisational effects that are presupposed with such an

organisational change. It must however be concluded that the centre after 1½ year has been able to fulfil the expectations regarding the organisational effects.

Patient

The purpose with "The Centre for pregnant women with a heart disease" is among other things to provide the pregnant woman with a higher degree of confidence and an improved treatment during their pregnancy and delivery.

The specialists assess that they are capable to offer a more coordinated supervision to the patients compared with the situation before the establishment of the centre. Furthermore, this shared effort by the specialist from the different departments does also result in an improved information and communication to the patients.

There was a tendency that women before the establishment of the centre did find the level of information given inadequate and with to little focus upon the fact that the women both were patients with a heart disease and at the same time pregnant. On the other hand there is a higher patient satisfaction with the level of information among the women in the period after the establishment. They are very satisfied with the coordination between the department of obstetrics and the department of cardiology, and feel that they to a higher degree are being listened to and taken seriously.

In general the patients feel – both in the period before and after the establishment of the centre – confident with their pregnancy and delivery. However, the higher degree of involvement of the women in the planning of the patient flow the higher degree of confidence.

The women in the period after the establishment of the centre have had a better experience with the pregnancy overall compared with the women in the period before. The women find it important that they see the same health professionals every time, and especially that it is the same midwife. All women express a wish for that there is a plan for the delivery and special arrangements made to approach eventual complication due to the heart disease.

The establishment of specific mother groups for pregnant women with heart diseases at the centre are needed in the future.

Economy

The centre is based on an existing budget for the treatment of the group of patients in focus. The establishment of the centre did not lead to an increase in the positions at Copenhagen University Hospital, and the establishment of the centre was not followed by any investment costs.

The study found a (non-significant) decrease in the number of outpatient visits and in the number of hospitalizations for the average patient in the period after the establishment of the centre compared with before. The implication of this is that the establishment of the centre has not increased the costs.

It seems fair to assume that the centre and the monitoring and follow-up of the pregnant women with heart diseases has resulted in a decrease in the number visits to the general practitioner and to the local hospital. The interviews with the patients support this assumption.

The patients experience less days, where they have to travel to the Copenhagen University Hospital, which mean a decrease in the cost of transportation compared with the situation before. This indicates a socioeconomic benefit for the society in terms of less days of absence from work (decrease in production loss) due to the improved planning of the patient flow in the centre.

Overall it is difficult to carry out specific economic calculations based on the available data material and with the lack of significant differences between the two periods. The conclusion with respect

to the consequences for the economy is therefore that all parts of the health technology assessment points in the direction that the centre has had positive economic consequences for all parties and levels of decision-making involved, i.e. the society, the health care sector, Copenhagen University Hospital and the patients.

Conclusion

Initially it should be concluded that pregnant women with a heart disease both before and after the establishment of The Centre for pregnant women with a heart disease has received good and safe monitoring and follow-up. After the establishment of the centre this monitoring and follow-up have, however, been much more co-ordinated than previously. This co-ordination of the patient flows do also in the future make it possible to provide good patient flows for pregnant women with a heart disease.

The present health technology assessment have – based on the conclusions made above – shown that it has been succeeded fulfil the purpose with the centre. With the centre a organisational constellation, which ensure that the pregnant women with heart disease gets the interdisciplinary monitoring and follow-up that is the prerequisite to obtain an optimal monitoring and follow-up of the mother and the child in a safely and coordinated patient flow.

The fact that the centre is based on changes in the organisation and the way of co-operating, illustrates how it has been possible within existing budgets to increase the quality of the treatment compared with before the establishment of the centre.

The centre is a good example of, how it is possible with the existing conditions and budgets to organise an improved co-operation and planning of patient flows without following old traditions and routines – this is both the case for the work with pregnant women with a heart disease as well as for other specialty areas in the health care sector.

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