



The ROPAC registry: a multicentre collaboration on pregnancy outcomes in women with heart disease

Matthias Greutmann^{1*} and Candice K. Silversides²

¹Adult Congenital Heart Disease Program, University Hospital of Zurich, Raemistrasse 100, 8091 Zurich, Switzerland; and ²University of Toronto Obstetric Medicine and Pregnancy and Heart Disease Programs Toronto Congenital Cardiac Centre for Adults, Mount Sinai Hospital and University Health Network, Toronto, Ontario, Canada

Online publish-ahead-of-print 9 October 2012

This editorial refers to ‘Outcome of pregnancy in patients with structural or ischaemic heart disease: results of a registry of the European Society of Cardiology’[†], by J.W. Roos-Hesselink et al., on page 657

The haemodynamic changes of pregnancy can have a negative impact on maternal cardiac health, especially in women with pre-existing cardiac disease. In the most recent Confidential Inquiries into Maternal Mortality in the United Kingdom, heart disease was found to be the most common indirect cause of maternal death during pregnancy.¹ Pregnancy counselling and management for women with heart disease is being increasingly recognized as an important aspect of their overall cardiac care. With increasing awareness, there has been a growing body of research focused on pregnancy outcomes and risk stratification. There have also been new initiatives to improve clinical care, such as the 2011 European Society of Cardiology (ESC) guidelines on the management of cardiovascular disease during pregnancy.² While our current understanding of pregnancy risk assessment and management has improved over the past 20 years, many questions can only be answered by collaborative efforts.

Roos-Hesselink and colleagues have now presented the first report of their multicentre, multinational Registry On Pregnancy and Cardiac disease (ROPAC) registry, supported by the ESC.³ The study is important because it provides a global perspective on pregnancy in women with heart disease. It included 1321 pregnancies in women from 28 countries, the majority of which were developed countries (86%) in Europe and North America. Most women from developed countries had underlying congenital heart disease (74%). In contrast, valvular heart disease was the predominant underlying cardiac condition (72%) in pregnancies reported from women in developing countries where rheumatic heart disease remains endemic. The study reports high rates of adverse maternal cardiac events during pregnancy including increased risk of maternal deaths. Hospital admission for cardiac reasons complicated 15% of

all pregnancies, primarily for treatment of heart failure. Similarly high event rates of adverse maternal cardiac events have been reported by other groups (Figure 1).^{4,5} Collectively, these studies highlight the need to identify women at highest risk and to develop care models to improve outcomes. Because maternal deaths at any one centre are relative rare, large multicentre registries such as this are necessary to study mortality outcomes. Although rare, maternal mortality (13/1321 pregnancies, 7 due to heart failure, 3 due to thrombo-embolic events, and 3 due to non-cardiac-related sepsis) was much more likely to occur in women with heart disease compared with the general population. While there are a number of risk scores for predicting adverse pregnancy outcomes in women with heart disease, this study externally validated the model proposed by the British Working Group, demonstrating its utility in predicting maternal mortality, the occurrence of heart failure, and fetal death.^{2,6}

Cardiac disease in pregnant women will probably be increasingly encountered in medical practice. With advances in cardiac surgery and improved childhood survival, there is a growing population of young women of childbearing age with congenital heart disease.^{7,8} Most of these women, particularly those with lesions of moderate or great complexity, have residua or sequelae that increase their risk of cardiovascular complications during pregnancy. Rheumatic heart disease, rare in developed countries, remains a major health problem in developing and underdeveloped countries. Women with rheumatic valve lesions such as mitral stenosis tolerate pregnancy poorly.⁹ The prevalence of ischaemic heart disease complicating pregnancies is increasing,^{1,10,11} perhaps related to trends in western societies of having children later in life and associated higher rates of cardiovascular risk factors in this older cohort. Further increases may occur with increasing assisted fertilization in older women. With this growing and evolving population, ongoing education of health care providers and patients is important.

Pre-conception counselling allows women to make informed pregnancy decisions, and risk stratification tools can be helpful to

The opinions expressed in this article are not necessarily those of the Editors of the *European Heart Journal* or of the European Society of Cardiology.

* Corresponding author. Tel: +41 44 255 3883, Fax: +41 44 255 8701, Email: Matthias.Greutmann@usz.ch

[†] doi:10.1093/eurheartj/ehs270.

Published on behalf of the European Society of Cardiology. All rights reserved. © The Author 2012. For permissions please email: journals.permissions@oup.com

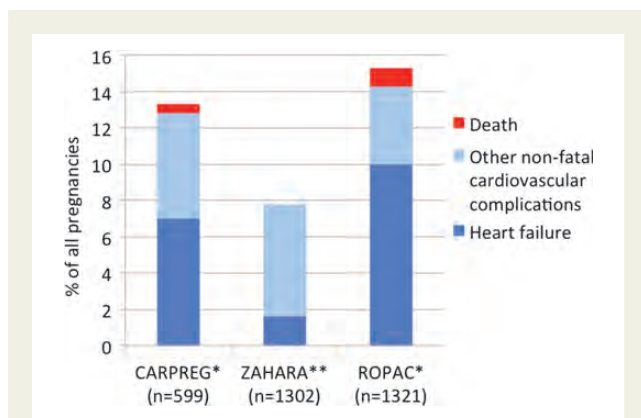


Figure 1 Risk of heart failure, other non-fatal adverse cardiovascular events, and maternal death in three large multicentre studies of pregnancy outcomes in women with heart disease. *The CARPREG study and the ROPAC registry include women with congenital and acquired heart disease. **The ZAHARA study included only women with congenital heart disease.

predict pregnancy risk. A number of risk stratification tools have been proposed to identify those women at highest risk.^{4–6,12} For some cardiac lesions, there is very little risk of adverse cardiac events during pregnancy, no special precautions are required during pregnancy, and women need nothing more than reassurance. In other cases, pregnancy poses a prohibitive risk and women need to be educated about the need to avoid pregnancy and about safe contraception options. Unfortunately, a number of groups have reported that women with heart disease often have inaccurate knowledge of pregnancy risk.^{13,14} Once pregnant, women identified as intermediate or high risk should receive coordinated care, with input from a cardiologist with expertise in pregnancy and heart disease, a high-risk obstetrician, and an obstetrical anaesthetist. To date, few studies have addressed delivery of care or quality of care in this high-risk population.

The ROPAC registry is likely to have many roles. As the registry increases in size, rare cardiac conditions or outcomes (such as maternal, fetal, or neonatal mortality) can be studied in more detail. The registry data can be used for validating and refining existing risk stratification scoring models or identifying novel risk markers derived from smaller mechanistic studies. The registry data can help to determine and compare regional treatment strategies and outcomes. Other parameters, such as healthcare costs, could be studied. The ROPAC registry is an important initiative that will help to improve the care of pregnant women with heart disease.

Conflict of interest: none declared.

References

- Cantwell R, Clutton-Brock T, Cooper G, Dawson A, Drife J, Garrod D, Harper A, Hulbert D, Lucas S, McClure J, Millward-Sadler H, Neilson J, Nelson-Piercy C, Norman J, O'Herlihy C, Oates M, Shakespeare J, de Swiet M, Williamson C, Beale V, Knight M, Lennox C, Miller A, Parmar D, Rogers J, Springett A. Saving mothers' lives: reviewing maternal deaths to make motherhood safer: 2006–2008. The Eighth Report of the Confidential Enquiries into Maternal Deaths in the United Kingdom. *BJOG* 2011;**118** Suppl 1:1–203.
- Regitz-Zagrosek V, Blomstrom Lundqvist C, Borghi C, Cifkova R, Ferreira R, Foidart JM, Gibbs JS, Gohlke-Baerwolf C, Gorenek B, Iung B, Kirby M, Maas AH, Morais J, Nihoyannopoulos P, Pieper PG, Presbitero P, Roos-Hesselink JW, Schaufelberger M, Seeland U, Torracca L, Bax J, Auricchio A, Baumgartner H, Ceconi C, Dean V, Deaton C, Fagard R, Funck-Brentano C, Hasdai D, Hoes A, Knuuti J, Kolh P, McDonagh T, Moulin C, Poldermans D, Popescu BA, Reiner Z, Sechtem U, Sirnes PA, Torbicki A, Vahanian A, Windecker S, Aguiar C, Al-Attar N, Garcia AA, Antoniou A, Coman I, Elkayam U, Gomez-Sanchez MA, Gotcheva N, Hifiker-Kleiner D, Kiss RG, Kitsiou A, Konings KT, Lip GY, Manolis A, Mebaaza A, Mintale I, Morice MC, Mulder BJ, Pasquet A, Price S, Priori SG, Salvador MJ, Shotan A, Silversides CK, Skouby SO, Stein JI, Tornos P, Vejlstrup N, Walker F, Warnes C. ESC Guidelines on the management of cardiovascular diseases during pregnancy: the Task Force on the Management of Cardiovascular Diseases during Pregnancy of the European Society of Cardiology (ESC). *Eur Heart J* 2011;**32**:3147–3197.
- Roos-Hesselink JW, Ruys TPE, Stein JI, Thilén U, Webb GD, Niwa K, Kaemmerer H, Baumgartner H, Budts W, Maggioni AP, Tavazzi L, Taha T, Johnson MR, Hall R. Outcome of pregnancy in patients with structural or ischaemic heart disease: results of a registry of the European Society of Cardiology. *Eur Heart J* 2013;**34**:657–665.
- Siu SC, Sermer M, Colman JM, Alvarez AN, Mercier LA, Morton BC, Kells CM, Bergin ML, Kiess MC, Marcotte F, Taylor DA, Gordon EP, Spears JC, Tam JW, Amankwah KS, Smallhorn JF, Farine D, Sorensen S. Prospective multicenter study of pregnancy outcomes in women with heart disease. *Circulation* 2001;**104**:515–521.
- Drenthen W, Boersma E, Balci A, Moons P, Roos-Hesselink JW, Mulder BJ, Vliegen HW, van Dijk AP, Voors AA, Yap SC, van Veldhuisen DJ, Pieper PG. Predictors of pregnancy complications in women with congenital heart disease. *Eur Heart J* 2010;**31**:2124–2132.
- Thorne S, MacGregor A, Nelson-Piercy C. Risks of contraception and pregnancy in heart disease. *Heart* 2006;**92**:1520–1525.
- Marelli AJ, Mackie AS, Ionescu-Ittu R, Rahme E, Pilote L. Congenital heart disease in the general population: changing prevalence and age distribution. *Circulation* 2007;**115**:163–172.
- Moons P, Bovijn L, Budts W, Belmans A, Gewillig M. Temporal trends in survival to adulthood among patients born with congenital heart disease from 1970 to 1992 in Belgium. *Circulation* 2010;**122**:2264–2272.
- Silversides CK, Colman JM, Sermer M, Siu SC. Cardiac risk in pregnant women with rheumatic mitral stenosis. *Am J Cardiol* 2003;**91**:1382–1385.
- Bush N, Nelson-Piercy C, Spark P, Kurinczuk JJ, Brocklehurst P, Knight M. Myocardial infarction in pregnancy and postpartum in the UK. *Eur J Cardiovasc Prev Rehabil* 2011; in press.
- Gelson E, Gatzoulis MA, Steer P, Johnson MR. Heart disease—why is maternal mortality increasing? *BJOG* 2009;**116**:609–611.
- Khairy P, Ouyang DW, Fernandes SM, Lee-Parritz A, Economy KE, Landzberg MJ. Pregnancy outcomes in women with congenital heart disease. *Circulation* 2006;**113**:517–524.
- Kovacs AH, Harrison JL, Colman JM, Sermer M, Siu SC, Silversides CK. Pregnancy and contraception in congenital heart disease: what women are not told. *J Am Coll Cardiol* 2008;**52**:577–578.
- Vigl M, Kaemmerer M, Seifert-Klauss V, Niggemeyer E, Nagdyman N, Trigas V, Bauer U, Schneider KT, Berger F, Hess J, Kaemmerer H. Contraception in women with congenital heart disease. *Am J Cardiol* 2010;**106**:1317–1321.