Asking questions about alcohol in pregnancy

Development of the AQUA study

Introduction

Exposure to alcohol in pregnancy can damage the fetus and affect the long-term development and health of that child.

Fetal Alcohol Spectrum Disorder (FASD) is an umbrella term to describe a number of outcomes thought to be associated with pregnancy alcohol exposure (PAE). These outcomes may include physical abnormalities (birth defects), as well as cognitive, behavioural and/or learning disabilities that may have lifelong implications. The evidence is clear that heavy and chronic alcohol consumption in pregnancy is associated with FASD, but the relationship between low to moderate levels of PAE or occasional binge drinking during pregnancy and outcomes for children is unclear.

This lack of clarity in research findings is pertinent when considering current policy in Australia and elsewhere that recommends abstaining from consuming alcohol during pregnancy as the safest option. The most important concern associated with the recommendation for abstinence is the high frequency of unplanned pregnancies and the strong possibility that many women may have consumed alcohol around the time of conception and well into the pregnancy before knowing they were pregnant. This creates difficulties for health professionals in counselling situations where, ill-equipped with evidence about the likelihood, severity and nature of adverse effects on the fetus and child, they may be asked to give advice about termination of pregnancy to women who are light and occasional drinkers. It also presents the potential for unnecessary guilt and anguish in pregnant women.

To this end, the National Health and Medical Research Council (NHMRC) guidelines for reducing health risks from drinking alcohol now include a section with practical advice for health professionals that states:

- the risk to the fetus is higher with high alcohol intake, including episodic intoxication, and appears to be low with low-level intake
- it is impossible to determine how maternal and fetal factors will alter risk in the individual.

In order to provide better evidence about the effects of low and moderate PAE, there is a strong need for a well-conducted Australian longitudinal study of pregnant women which includes detailed reporting and documentation of maternal alcohol consumption. The study design should include a clearly defined classification of alcohol exposure levels, and must take into account other factors that can influence the effects of alcohol (such as smoking or family history).

With funding from VicHealth, the Murdoch Childrens Research Institute, in collaboration with experts in other states, prepared to conduct such a study of pregnant women and their babies.

Development: a two stage process

In 2010 the focus of the project was to firstly address the need for a best possible assessment of PAE. This involved the development of a set of questions to:

- accurately and sensitively elicit information about alcohol use in pregnancy
- record other factors that are known to modify or mediate alcohol-related outcomes, such as diet, smoking and family history.

A detailed review of the literature provided information about what 'other factors' should be captured in the study's questionnaire design. The main challenge however, was to develop a set of questions that accurately and sensitively elicited information about alcohol use in pregnancy. These questions needed to be able to discriminate between low, moderate and high alcohol consumption around the time of conception and throughout the pregnancy and also include information on dose, frequency, pattern and duration of alcohol use. The questions were developed over a two-stage process.

First, a comprehensive literature review of existing measures of alcohol consumption in pregnancy was conducted. This review highlighted the need for a tool that obtained information in a manner that reflected real life drinking patterns, and one that was designed specifically to gather accurate data on all alcohol consumption levels, not just high risk patterns such as binge drinking and chronic use. Using information gained from the review, questions and an accompanying pictorial 'drinks guide' were developed. The guide incorporates popular drinks not included in older research designs (e.g. mixed drinks, low strength beers and ciders), thereby promoting accurate reporting of alcohol use and informing the development of precise dose ranges (measured as grams of alcohol per occasion).

Ensuring the questions were acceptable to potential participants and encouraged accurate reporting was of vital importance to the study. Therefore, the second stage of this process involved conducting six focus groups with pregnant women who would potentially be eligible for the study. The draft questions and the drinks guide were presented to these groups to explore the women's views on the best way to ask these questions.

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The women in the focus groups responded positively, expressing the belief that they could respond honestly to the questions. The women felt *"The questions are more focused around quantifying (alcohol intake) rather than asking opinions about it. So it takes that judgemental aspect away from it."* Another said, *"It's just collecting data, not pointing the finger."*

Comments from focus group participants were also used to fine tune the instrument in cases where additional context needed to be provided or where the language was too complex or appeared subjective.

By developing the alcohol questions and drinks guide in consultation with women who would be eligible for our proposed study, some of the inherent barriers to recruiting study participants and obtaining accurate self-report data were now removed.

Outcomes

A new set of alcohol questions and significant national funding

The first key outcome from the preliminary work funded by VicHealth was the new set of alcohol consumption questions, able to be included in a full questionnaire and used with a pictorial drinks guide. Importantly, in the process of achieving this outcome, a strong collaboration of experts was established, and this team has now been successful in obtaining $1.3 million from the NHMRC to undertake the pregnancy cohort study from 2011.

The funding will be provided over four years and allow the study to include about 2000 women during the early, mid and late stages of their pregnancies. A range of outcomes on health and development will be measured for all the babies at one year of age using a questionnaire.

In addition, a sample from each of a number of different exposure groups (e.g. low versus moderate maternal alcohol consumption) will have 3D pictures of the face taken to look for subtle neuroanatomical changes. At two years of age this same sample of children will undergo a developmental assessment. These facial and developmental measures are suitable for use in a clinical setting and have the potential to assist in the early diagnosis of FASD, allowing for early treatment to minimise the adverse outcomes associated with the disorder.

The pregnancy cohort study will provide new evidence that will contribute to policy review and development, health professional education and consumer information about alcohol consumption for women during pregnancy. The knowledge gained will allow both women and men to be better informed of the risks of maternal alcohol consumption in pregnancy, and will be particularly relevant to women planning a pregnancy and those who have consumed alcohol before knowing they were pregnant.

Wider-reaching collaborations

Another key outcome from the VicHealth-funded literature review and question development work has been the integration of the project with two important national collaborations on aspects of FASD. The first is a collaboration with the Australian Institute of Health and Welfare, National Perinatal Statistics Unit (NPSU) to assist in development of data items on PAE to inform 'Closing the Gap', the COAG National Indigenous Report Agreement. The outcome will be an agreed standardised approach across Australia for the collection and reporting of data items related to alcohol intake in pregnancy, resulting in improved data to support policy development, education and planning.

The second important relationship involves a consultancy role with the Australian FASD Collaboration funded by the Commonwealth Department of Health and Ageing. This Collaboration is funded to develop a screening and diagnostic instrument for FASD in Australia. Currently there is suboptimal identification of babies and young children with FASD, making it impossible to quantify the problem and plan appropriate support services and health professional training. At the conclusion of this project it is expected that there will be a clear methodology in place for diagnosis of FASD that will ultimately improve health outcomes and quality of life for individuals affected by FASD and their families.

Conclusion

The contribution VicHealth has made to this field of research has been substantial; without the support to ensure optimal study design for the cohort study, Victoria would not be participating in the national efforts to prevent adverse health outcomes in children caused by alcohol exposure in pregnancy. The collaborations and relationships fostered as part of this process mean that the knowledge and expertise accumulated have broader implications for national diagnosis, treatment and policy development initiatives.

For more information about the continuing project – **AQUA** – **A**sking **QU**estions about **A**lcohol in pregnancy, please visit the website www.mcri.edu.au/aquastudy