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Prenatal treatment of Congenital Adrenal Hyperplasia (CAH): A survey of Paediatric Endocrinologist

Ethical group of Sociedad Española de Endocrinología Pediátrica (SEEP)

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Introduction

Prenatal dexamethasone (DXM) treatment has been proposed to prevent genital virilization in girls with CAH, however its safety has been questioned for potential adverse effects on the fetus and the mother.

Objectives

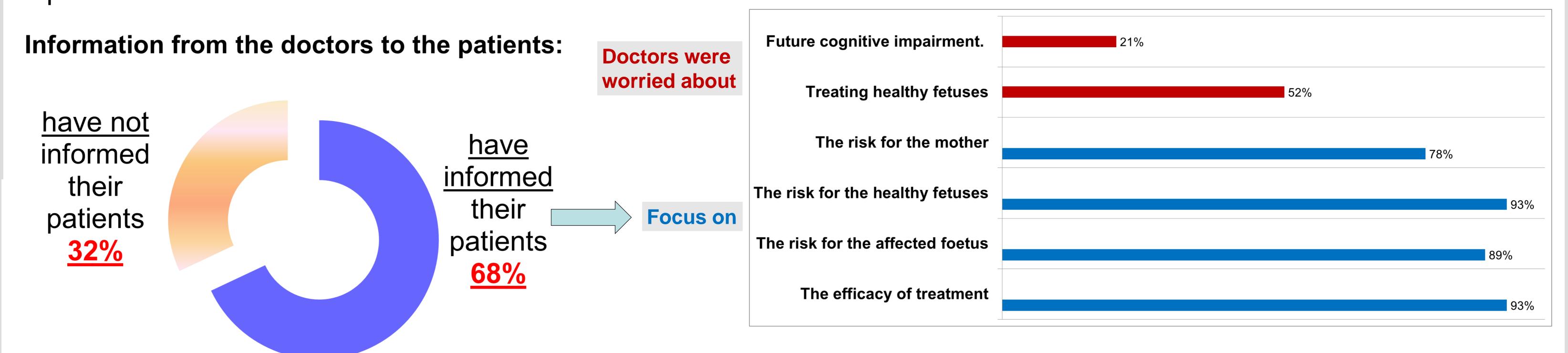
To analyse clinical practice (kind and amount of information given) and prenatal treatment experience with DXM during pregnancy at risk of having her daughters with severe CAH.

Methods

An online survey to all members of SEEP was conducted to analyse the information process to parents, monitoring of prenatal and postnatal treatment and ethical issues raised by this action.

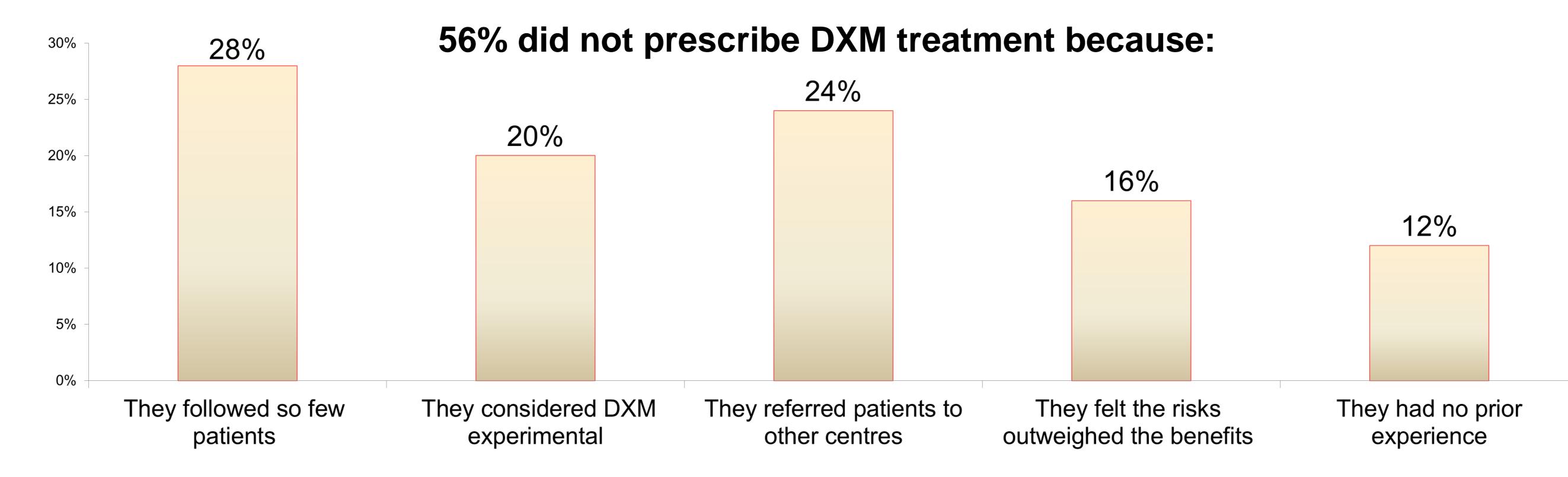
Results

The questionnaire was sent to 248 Spanish paediatric endocrinologists. There were 49 responses (20%) from all over the country. 64% from reference centres for CAH, or tertiary hospitals. Of the sample, three participants were treating more than 20 patients affected with CAH.



38% conducted a meeting with endocrinologists, and/or gynaecologists to explain the treatment; 35% provided verbal and written information to obtain an adequate informed consent.

54% of paediatric endocrinologists have ever been consulted at some time about prenatal treatment of CAH. 34% said that treatment was given at their hospital.



70% respondents considered that treatment should remain experimental.

Conclusions

Index of response was very low; the majority have limited experience about CAH and/or prescription Most practitioners consider this treatment experimental

It would be necessary that working groups who are investigating, publish their results and the best course to follow is clarified