

INTRODUCTION

Autoimmune hepatitis (AIH) is a chronic autoimmune liver disease which, if left untreated, progresses to fibrosis and cirrhosis.

First line treatment

Induction of remission with steroids followed by addition of a steroid sparing agent

Goal of treatment

Complete biochemical and histological remission.

Treatment failure

- True failure to respond to first line treatment is rare
- Poor disease control is most commonly due to **poor adherence** to therapy and intolerance of medication due to **side effects**

AIMS

- 1) Identify current practice around steroid use in the UK
- 2) Establish frequency and type of steroid related side effects and related changes to treatment
- 3) Establish patient perspectives on quality of information provision
- 4) Identify areas of information need

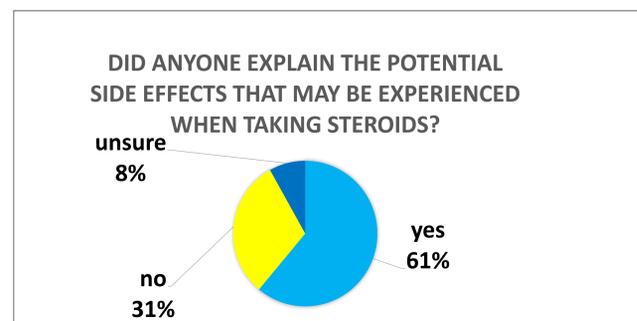
METHODS

- An online questionnaire was sent to all members of the AIH support group
- 185 responses were received
- Respondent characteristics
88% female
Mean age 49

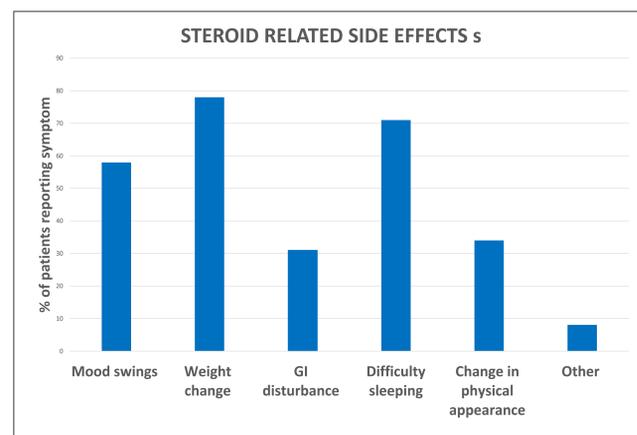
RESULTS

STEROID RELATED SIDE EFFECTS

182 respondents had been started on treatment
162 were started on prednisolone as first line
13 received budesonide as first line



178 respondents (97%) reported at least one steroid related side effects

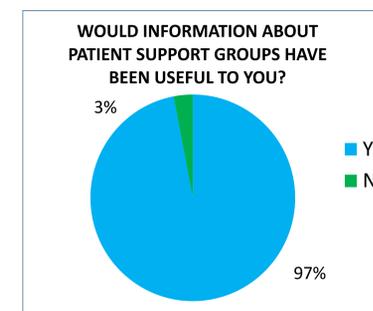
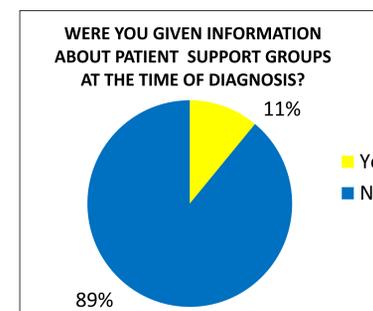
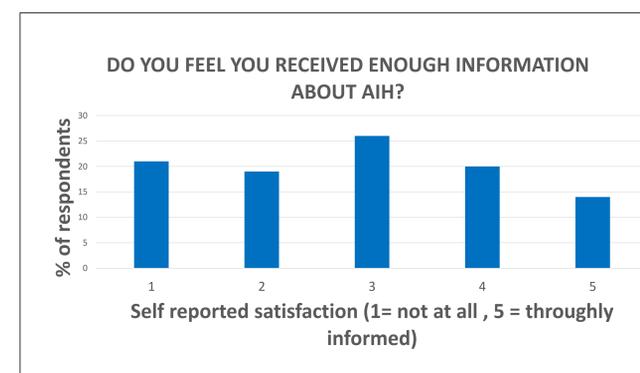


133/178 (75%) reported the side effects to their doctor
18/133 (14%) cessation of steroids as a result of side effects

Reasons given by respondents for carrying on with steroids:

- Necessary to treat disease (n=26)
- Side effects are normal and expected (n=19)
- Side effects were mild (n=8)
- No alternative available (n=6)

SATISFACTION WITH INFORMATION PROVISION



Areas where respondents felt they would benefit from more information included:

- Treatment options and side effects
- Long term prognosis
- Relevant lifestyle factors
- Current research
- Interpretation of blood results
- Fertility and future pregnancy
- Travel insurance

CONCLUSIONS

TREATMENT

Corticosteroid related side effects were encountered by the majority of respondents to this study.

> 30% reported that the side effects of steroids were not explained to them prior to the start of treatment.

In line with published literature (which suggests that steroid side effects lead to discontinuation in 15% of patients¹), 14% of respondents to this survey reported that their treatment was stopped or altered as a result of side effects.

>70% carried on with treatment despite side effects.

Use of budesonide was reported by only a small number of respondents. There is potential for increased use of this as an alternative to prednisolone.

INFORMATION

Survey responses highlighted variable satisfaction with the quality of information provided to patients by clinicians.

There was commonality of areas where respondents felt information could be improved.

Patient groups play an important role in information provision and patient support. Awareness amongst clinicians around the importance of directing patients to these groups needs to be increased.

REFERENCES

1. EASL Clinical Practice Guidelines: Autoimmune Hepatitis. Journal of Hepatology. 2015; 63: 971-1004

ACKNOWLEDGEMENTS

This survey was conducted by AIH Support and funded by Dr Falk Pharma. MC and GH are funded by the National Institute for Health Research (NIHR) Birmingham Liver Biomedical Research Unit programme. The views expressed are those of the authors and not necessarily those of the NHS, NIHR or the Department of Health.

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