

Behavioural research into adrenal insufficiency (AI) patients' perceptions of AI medication, symptoms and adherence: results of a multi-country, European online survey

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INTRODUCTION

Previous qualitative studies have explored perceptions of medication among patients with adrenal insufficiency (AI) as possible determinants of treatment satisfaction.

To our knowledge, this study is the first to quantify AI patients' perceptions of their medication and condition in relation to their adherence to taking their medication as prescribed.

Several models and frameworks have been developed to explain adherence to medication. This study used the Perceptions And Practicalities Approach (PAPA)¹ and the Necessity-Concerns Framework (NCF)² to identify potential modifiable determinants of medication behaviours and preferences.

METHOD

70 participants met the inclusion criteria (aged 18 and over, diagnosed with AI and treated with a conventional hydrocortisone replacement therapy). 11 participants were excluded from the study. Participants had a mean age of 47.4 years ($SD = 14.4$, range = 22 years to 73 years), and the majority of the participants were female (68.6%).

Participants were recruited in May 2013 from European patient support groups. An online self-report survey was used and included validated questionnaires that have been shown to be predictive of adherence to medication (Beliefs about Medicines Questionnaire³ and Satisfaction with Information about Medicines Scale⁴). The Medication Adherence Report Scale⁵ was adapted and used to report adherence to medication.

The results of the survey are described using means and standard deviations for continuous, normally distributed data. Modes or medians were used where data was not normally distributed. Logistic regression and correlations were used to investigate relationships between variables.

RESULTS

The sample resided in the UK ($n=20$), Germany ($n=9$), France ($n=18$), Sweden ($n=12$) and Spain ($n=11$). The majority of the sample were prescribed medication twice or three times daily, and they had been taking their medication for more than two years (see Table 1).

Responses to an adapted version of the medication adherence report scale (MARS) showed this group of participants were high adherers to their medication ($Mdn = 36$). However, dichotomising the results into two groups: low adherers (score $<32/40$) and high adherers ($\geq 32/40$) showed that 30% ($n=21$) were low adherers. The most frequent types of non-adherence behaviours reported were 'I take my dose later in the day than advised' and 'I take my dose at a different time of day than advised'.

Beliefs about medication indicated that although most participants were convinced of their personal need for AI medication, more than a third (37.1%, $n=26$) expressed doubts about the need for strict adherence to dose timings, reporting sometimes/always/often taking their dose at a different time of day than advised (see Figure 1). Two thirds of participants (64.3% $n=45$) reported strong concerns about their medication. No significant relationships were found between adherence and beliefs about medication.

Participants reported more dissatisfaction with information about potential problems than information about action/usage of their AI medication (see Figure 2). In particular, participants who were dissatisfied with information about the potential problems they might experience were at greater risk of low adherence, such that for each piece of information they were not satisfied with, the odds of low adherence increased by 1.52, $p < 0.001$.

Further, moderate relationships were also found between dissatisfaction with information about potential problems of taking AI medication and higher concerns, $r(70)=0.375$, $p=0.001$, and dissatisfaction with information about the action/usage of AI medication and higher concerns, $r(70)=0.297$, $p=0.001$.

TABLE 1: Current medication for AI

Current maintenance medication for AI	n (%)
Twice daily hydrocortisone (immediate release tablets)	37 (52.9%)
Three times daily hydrocortisone (immediate release tablets)	30 (42.9%)
Prednisolone	1 (1.4%)
Cortisone acetate	1 (1.4%)
Time taking current medication for AI	n (%)
6 months-2 years	6 (8.6%)
> 2 years	64 (91.4%)

Note: One person stated 'other' and did not specify their current maintenance medication

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FIGURE 1. Proportion of participants ($n=70$) saying that they 'sometimes, often or always' took their regimen in ways other than advised when responding to the MARS scale⁵. The most frequent types of non-adherence reported were 'I take my dose later in the day than advised' and 'I take my dose at a different time of day than advised', suggesting that timing was a particular issue for participants taking their AI medication.



FIGURE 2. Dissatisfaction with information about potential problems with AI medicines as measured by SIMS potential problems subscale⁴. Participants ($n=70$) who stated that they had received 'too much', 'too little' or 'none' about each type of information were classed as dissatisfied whereas those who stated that the information was 'about right' or endorsed 'none needed' were classed as satisfied.



CONCLUSIONS

There are considerable unmet needs in this European sample of AI patients that are leading to poor adherence, including dissatisfaction with information and high concerns about potential adverse effects.

The current findings suggest that most patients are adherent to their medication overall due to a high need for treatment despite the prevalence of concerns they have about taking their treatment. However, given the prevalence of concerns it is evident that these participants may remain worried about their illness and the potential adverse effects of their treatment.

Further, as participants are reporting dissatisfaction with much of the current information available to patients about AI and its treatment, this could indicate that patients are not understanding the consequences related to altering their dosing and thus not alleviating the concerns they have about their medication. These beliefs are associated with poorer adherence.

Where there is low adherence, participants are reporting sub-optimal adherence behaviours such as adjusting the time of day the medication is taken. The result suggests that timing is a particular issue for these participants taking their AI medication. It is possible that this non-adherence to timing may increase the impact of the disease, such as weight gain and fatigue, and put patients at risk of more serious adverse effects.

Lastly, the results illustrate heterogeneity among people diagnosed with AI in terms of perceptions and behaviour related to their AI. Unfortunately the sample size was not sufficiently large to fully investigate the heterogeneity nor any small associations between variables.

Overall, these results suggest that there may be value to patients in providing better information about the potential problems of AI medication, and tailoring treatment choice and/or information about treatments for each individual patient to address specific concerns due to treatments and the consequences of non-adherence to timing.

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