A glucocorticoid education group meeting: an effective strategy for improving self-management to prevent adrenal crisis

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Abstract

Objective: To assess self-management in patients receiving glucocorticoid replacement therapy for primary or secondary adrenal failure before and 6 months after a glucocorticoid education group meeting.

Methods: All patients with primary or secondary adrenal insufficiency, treated at the department of Medicine, Division of Endocrinology were invited by their endocrinologist to participate in a three-hour glucocorticoid education group meeting, consisting of a lecture about the disease and glucocorticoid doses adjustments in case of stress, followed by an instruction how to inject hydrocortisone intramuscularly. Finally, all participants could practice the intramuscular injection and discuss their experience with (imminent) adrenal crises with other patients and the health care providers. Two weeks before the meeting and 6 months after the meeting, patients were asked to fill out a questionnaire about how they would act in 6 different conditions (e.g. febrile illness or vomiting).

Results: Of the 405 patients who were invited, 246 patients (61%) participated. At baseline the response by the participants on the questionnaire was 100% (N=246) and at follow-up 74% (N=183). At follow-up, significantly more participants (p=<0.005) gave the correct answers how to act in the different situations (e.g. self administration of a glucocorticoid injection and phone contact in case of vomiting/diarrhoea without fever). Moreover, the use of self-management tools, such as having a ‘medicine passport (travel document with information about disease and medication) (p=0.007) or SOS medallion (p=0.0007)’ increased.

Conclusion: A glucocorticoid education group meeting for patients with adrenal failure seems helpful to improve self-management and proper use of stress-related glucocorticoid dose adjustment.
Introduction

Adrenal insufficiency is caused by disease of the adrenal glands (primary adrenal failure) or disease of the hypothalamic-pituitary system (secondary adrenal failure). More women than men are affected. Both patients with primary and secondary adrenal insufficiency require lifelong substitution therapy with glucocorticoids.

When glucocorticoid substitution is insufficient in these patients, a so-called adrenal crisis can occur. It is well known that endogenous cortisol secretion increases substantially in response to stressful events in healthy subjects. In parallel, patients with adrenal insufficiency have to increase their glucocorticoid dose adequately in case of stressful situations, such as (febrile) illness, to respond to the increased demand and to prevent adrenal crisis. Proper information to patients and their relatives on ‘sick rules’ is of utmost importance to prevent life-threatening adrenal crises. In fact, patient education is considered the most important preventive measure.

Self management for people with chronic health problems is widely recognized as a necessary part of treatment. The patients are responsible for the day-to-day management of their illness. In order to effectively self manage their disease, people should acquire the necessary knowledge and skills. Professional support with self management is an essential component of high quality care for long term conditions. In patients with other chronic diseases, group education programs have proved to increase knowledge.

Previous studies in patients with adrenal insufficiency concluded that patients have a lack of knowledge concerning adequate self management, and the need for continuing and effective education was recommended. To our knowledge the efficacy of a group-based glucocorticoid education meeting has never been evaluated.

The aim of this study was to assess the self management in patients with adrenal insufficiency before and 6 months after a glucocorticoid education group meeting.
Methods

Design
A longitudinal questionnaire-based intervention study at the Radboud University Nijmegen Medical Centre.

Participants
This survey was carried out at the out-patient clinic of the Department of Medicine, Division of Endocrinology at the Radboud University Nijmegen Medical Centre in the Netherlands. All patients visiting the out-patient clinic in the period April 2009 until February 2011, aged >18 years and treated with glucocorticoid substitution therapy for primary or secondary adrenal insufficiency, were informed by their endocrinologist about the group education. The endocrinologists stressed the importance of attending to the meeting and patients were handed over an envelope with an information letter about the study, a registration form and the program of the group meeting. Most of the patients had visited the clinic regularly for several years, generally once or twice a year, and had been seen at least once within a year of the time of the study. Patients were invited to bring along a partner or a close friend. A total of 405 patients received the information letter.

As medical treatment was not modified for this study and filling-out a questionnaire on self management was not seen as burdensome, the study proposal was not presented to the local medical ethics committee.

Intervention
The three-hour glucocorticoid education group meeting (12-14 patients per meeting) consisted of a lecture about the disease, its treatment and instructions on ‘sick rules’: the recommended stress-related glucocorticoid dose adjustment. These instructions, as used at the department of Endocrinology, are: hydrocortisone 60 milligram in the morning and 30 milligram in the afternoon, or an equivalent dose of any other glucocorticoid in case of fever (over 38°C) or serious mental stress (the passing of a close family member or difficult exams). In case of inability to retain medication
(vomiting, diarrhoea) an intramuscular injection with hydrocortisone is prescribed, and patients are told to have telephone contact with the hospital after the injection. Patients can consult the endocrinologist on-call by telephone 24 hours a day and 7 days a week.

The nursing education consisted of an instruction (illustrated by a video) how to inject hydrocortisone intramuscularly. Supervised by nurses, all patients and their guests could practice this action during the meeting. Furthermore, during the meeting patients could discuss their experience with (imminent) adrenal crises with other patients and the health care providers.

**Measurement**

*Questionnaires*

Two weeks before, and 6 months after the meeting, patients were invited to fill out a questionnaire.

The questionnaire, used in the study of Flemming et al \(^{11}\), was adapted for the Dutch population by the researcher (H.R-W.) and reviewed by four endocrinologists and two nurse specialists of the Department of Medicine, Division of Endocrinology. Besides patients characteristics, the questionnaire consisted of six hypothetical conditions of illness. For each hypothetical condition patients were first asked whether they would take action. If patients confirmed, they were asked to describe what the action would be.

The hypothetical conditions were: (I) increased daily hazzles at work or at home but no intercurrent physical illness; (II) common cold or coughing and a temperature below 38.0 C; (III) flu and a raised temperature of ≥ 38.0 C; (IV) a single vomiting just after ingesting the usual morning dose; (V) repeated vomiting or diarrhoea and a temperature below 38.0 C; and (VI) repeated vomiting or diarrhoea and a raised temperature above 38 C. \(^{11}\)

Furthermore, patients were asked to agree or disagree to the following questions: (a) whether the level of information concerning the treatment so far was considered satisfactory; (b) whether they had the glucocorticoid instruction leaflet and ampoules of hydrocortisone at home; (c) whether they had practiced the intramuscular injection; (d) and whether they had a “Medicine passport” and (e) a
so called ‘SOS medallion’. A “medicine passport” is a travel document with information on the disease and the prescribed medication.

After the last session of the glucocorticoid education group meetings (February 2011), the non-participants (N=159) were also invited to fill out the baseline questionnaire

Socio-economic variables

The socio-economic variables included were gender, age, relationship and education. Relationship was classified as living with or without a partner. Educational level was classified as primary, secondary and tertiary educational level, representing 7, 12, and 17 years of education, respectively.

Data Analysis

Statistical analyses were performed using SAS® 9.2. Reference answers for the hypothetical conditions were based on the recommendations. In hypothetical condition I – II no action had to be taken and for condition III – VI action is essential. All written answers to the open questions on the severest hypothetical conditions V and VI were categorized into 4 categories, namely: 1) injection and phone contact with either general practitioner or endocrinologist, 2) injection only, 3) phone contact only and 4) others.

For testing the differences between subject groups Student’s t-test is used for age, Wilcoxon’s test for disease duration, and Fisher’s exact test for nominal data. For the differences in binary outcome variables between baseline and follow-up measurements, Mc-Nemar’s test was used. P < 0.05 was considered to be statistically significant.
Results

Respondents

Of the 405 patients who were invited, 246 patients (61%) participated in the glucocorticoid education group meetings. At baseline, the response of the participants to the questionnaire was 100% (N=246) and at follow-up 74% (n=183). The non-participants were invited to complete the questionnaire after February 2011. The number of responders among the non-participants, called responders, was 44/159 (28%) (Figure 1).

Figure 1

Table 1 shows the baseline characteristics of the participants (N=246) and the non-participants for age, gender and type of disease and the baseline characteristics of the participants (N=246) and responders (N=44) for disease duration, relationship and educational background. Compared to responders, participants were significantly older, lived more frequently together with a partner and had more frequently secondary adrenal insufficiency.

Table 1

Self-management: action

At baseline no significant differences were found between participants and responders with respect to their answers on the hypothetical conditions, except for hypothetical condition III. Significantly more participants mentioned taking action in case of ‘flu and a raised temperature ≥ 38.0 C’ compared to the responders (p=0.003) (data not shown in table).

At follow-up, compared to baseline, significantly more participants mentioned to take action for the hypothetical condition IV ‘a single vomiting just after the usual morning dose’ and the hypothetical condition V ‘repeated vomiting or diarrhoea and a temperature below 38.0 C (p= 0.03 and <0.03 respectively) (Table 2).

Table 2

Self-management: detailed answers about interventions
For the mildest hypothetical condition (I), ‘increased daily hazelles at work or at home but no intercurrent physical illness’, 54% (baseline) and 50% (follow-up) of the participants and 48% of the responders answered that they would take action, and in 80% of these cases oral medication was increased.

For the most severe hypothetical conditions (V +VI), ‘repeated vomiting or diarrhoea and a temperature below 38.0 C’ or above 38 C’, participants and responders scored similarly at baseline (p=0.36 and p=0.34, respectively). At follow up, significantly more participants gave the correct answer (‘injection and phone contact’) (p=<0.005 and p=0.02 respectively; Figure 2)

Figure 2

Self-management: tools

At baseline no significant differences were found for the self-management tools between participants and ‘responders’, except for the level of information. The ‘responders’ were significantly more satisfied about the information they had received in the past (p<0.001). Between baseline and follow-up the participants differed significantly for all self-management tools except for having ampoules of hydrocortisone at home (Table 3).

Table 3

Discussion

This is the first study that assessed the self-management for ‘sick rules’ in patients receiving replacement therapy for adrenal insufficiency before and 6 months after attending a glucocorticoid education group meeting. Goal of this meeting was to provide patients and their family and friends with more information and management tools in order to be able to act adequately in case of (imminent) adrenal crisis.

The results show that at follow-up the reported self-management of patients receiving replacement therapy with glucocorticoids had improved. Most importantly, significantly more participants mentioned to take correct action (i.e. injection and phone contact) in case of repeated vomiting or diarrhoea, a potential life-threatening situation for these patients. Furthermore, after participating in
the meeting, significantly more participants mentioned to have adequate self-management tools such as a glucocorticoid instruction leaflet and a Medicine passport or SOS medallion. Almost all participants had the ampoules of hydrocortisone at home at baseline as well as at follow-up. Having hydrocortisone ampoules and a glucocorticoid instruction leaflet at home is not only important for self-management, but could also improve the emergency care provided by a health care provider at home (particularly important when the emergency doctor is not familiar with the condition).

Interestingly, half of the patients reported to increase their glucocorticoid dose in case of increased stress at work or at home (without intercurrent illness), although this is not recommended and could even contribute to long-term side effects of glucocorticoid therapy, such as weight gain, osteoporosis and vascular disease.\textsuperscript{15}

Patients’ knowledge about ‘sick rules’ has been investigated before, generally showing suboptimal responses to hypothetical cases. Peacey et al (1993) studied patient response to hypothetical illnesses. In the hypothetical case of vomiting they showed that only 62% of the 60 included patients on replacement therapy would seek medical attention in case of vomiting (appropriate answer to vomiting was to seek medical advice early).\textsuperscript{12}

Flemming & Kristensen (1999) also performed a questionnaire-based survey among 97 patients on hydrocortisone treatment.\textsuperscript{11} They found that only 54% of the 84 patients could be classified as reacting appropriately according to their criteria. Although the definition of appropriate intervention varies between these studies, it can be concluded that the result of regular patient education is still suboptimal. Interestingly, reference answers to the hypothetical illness varies largely amongst the studies: In Peacey et al\textsuperscript{12} the appropriate answer to ‘vomiting’ was seeking medical advice early. In Flemming et al\textsuperscript{11} the appropriate answer to ‘repeated vomiting’ was doubling of the usual dose and seeking medical assistance in the absence of improvement. In our study, the correct answer to the same condition was injection of hydrocortisone intramuscularly and phone contact. These differences probably reflect the developments in patient education: today, it is more common to
teach patients and their carers how to inject hydrocortisone in case of emergency (Wass & Arlt 2012). It is generally accepted that patient education is crucial in attaining an adequate level of self-efficacy. Several strategies have been used for patient education. Fleming et al (2011) performed a study to assess caregiver (i.e. parents) knowledge and their confidence in managing adrenal crisis and stress dosing of children with congenital adrenal hyperplasia. They concluded that caregivers who received written instruction and demonstration of injection technique scored significantly higher in self-efficacy for managing adrenal crisis in general and the injection procedure. Our glucocorticoid education meeting (for adult patients and their family) did not only consist of injection training, but also of a lecture with background information. It was not possible to assess the effects of the separate components of the meeting, but we hypothesize that also theoretical background information can contribute to self-efficacy. Involving family members in training adult patients is less self-evident (then in young patients), but could also contribute to better self-management at home.

Patient education group meetings have been shown to be effective for people with type 2 diabetes mellitus, improving knowledge and self-management. We found that patients highly appreciated the presented background information about adrenal insufficiency and it was subject of discussion between patients. Also, exchanging personal experiences between patients was of additional value. In addition, the setting of a group meeting enabled the health professional to present a patient case of adrenal crisis with fatal outcome. We judged that the presentation of a fatal case is less suitable for an individual interview but could serve well as an illustration of the importance of adequate self-management in a group meeting.

A limitation of our study is the fact that it was performed in one centre, which may limit the external validity of the study findings. Second, patients were asked to provide written answers to the questions (open questions) and these answers had to be categorized afterwards. Third, we would
rather have used ‘hard’ outcome variables such as hospitalisation or frequency of adrenal crisis, but considering the low numbers of patients this was not feasible in this study.

The importance of patient education about measures to prevent adrenal crisis has been stressed by several recent publications (Wass & Arlt, 2012; Reisch et al., 2012). Hahner et al. (2010) concluded that only a limited number of risk factors were suitable for targeting prevention of adrenal crisis and that new concepts of crisis prevention are needed. Moreover, they recommended validated structured education of patients, more widespread provision with an emergency glucocorticoid set for i.v. administration and education of family members including training in the use of emergency glucocorticoids. We would suggest that glucocorticoid education group meeting could address several of these targets, with the additional advantage of interaction between patients.

For the non-responders we suggest an individual counselling strategy by a nurse specialist, a strategy that is now utilized in daily practice at the out-patient clinic of our department.

In conclusion, our study showed that glucocorticoid education group meetings could help to improve patients’ self-management to prevent adrenal crisis.

DECLARATION OF INTEREST

The authors declare that there is no conflict of interest that could be perceived as prejudicing the impartiality of the research reported.

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**Table 1.** Patient characteristics at baseline; participants, non-participants and responders

<table>
<thead>
<tr>
<th></th>
<th>Participants (N=246)</th>
<th>Non-participants (N=159)</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Age, years (mean ± SD)</strong></td>
<td>49.7±15.0</td>
<td>45.2±17.6</td>
<td>0.01</td>
</tr>
<tr>
<td><strong>Gender, ☀ (%)</strong></td>
<td>57</td>
<td>47</td>
<td>0.08</td>
</tr>
<tr>
<td><strong>Disease:</strong></td>
<td></td>
<td></td>
<td>0.02</td>
</tr>
<tr>
<td>Primary adrenal insufficiency (%)</td>
<td>29</td>
<td>41</td>
<td></td>
</tr>
<tr>
<td>Secondary adrenal insufficiency (%)</td>
<td>71</td>
<td>59</td>
<td></td>
</tr>
<tr>
<td><strong>Participants (N=246)  Responders (N=44)</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Disease duration, years (mean ± SD)</strong></td>
<td>17.0±12.8</td>
<td>19.7±11.6</td>
<td>0.12</td>
</tr>
<tr>
<td><strong>Relationship (living with partner) (%)</strong></td>
<td>63</td>
<td>47</td>
<td>0.04</td>
</tr>
<tr>
<td><strong>Educational background:</strong></td>
<td></td>
<td></td>
<td>0.39</td>
</tr>
<tr>
<td>• Primary (%)</td>
<td>20</td>
<td>30</td>
<td></td>
</tr>
<tr>
<td>• Secondary (%)</td>
<td>49</td>
<td>42</td>
<td></td>
</tr>
<tr>
<td>• Tertiary (%)</td>
<td>31</td>
<td>28</td>
<td></td>
</tr>
</tbody>
</table>

p-values were tested with: * Student’s t-test, ** Fisher’s exact, *** Wilcoxon’s test
**Table 2.** Six hypothetical conditions: actions of participants who completed both questionnaires at baseline and at follow-up (N=183) Results are percentages (N) for correct answers

<table>
<thead>
<tr>
<th>Condition</th>
<th>Baseline</th>
<th>Follow-up</th>
<th>p-value (Mc-Nemar)</th>
</tr>
</thead>
<tbody>
<tr>
<td>(I) increased daily hassles at work or at home and no intercurrent physical illness</td>
<td>54 (175)</td>
<td>50.0 (175)</td>
<td>0.27</td>
</tr>
<tr>
<td>Ref.: no action</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>(II) common cold or coughing and a temperature below 38.0 C</td>
<td>84 (181)</td>
<td>85.7 (181)</td>
<td>0.72</td>
</tr>
<tr>
<td>Ref.: no action</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>(III) flu and a raised temperature ≥ 38.0 C</td>
<td>96 (179)</td>
<td>97(179)</td>
<td>0.41</td>
</tr>
<tr>
<td>Ref.: action has to be taken</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>(IV) a single vomiting just after ingesting the usual morning dose</td>
<td>77 (166)</td>
<td>84 (166)</td>
<td>0.03</td>
</tr>
<tr>
<td>Ref.: action has to be taken</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>(V) repeated vomiting or diarrhoea and a temperature below 38.0 C</td>
<td>92 (169)</td>
<td>96 (169)</td>
<td>&lt;0.03</td>
</tr>
<tr>
<td>Ref.: action has to be taken</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>(VI) repeated vomiting or diarrhoea and a raised temperature above 38 C.</td>
<td>96 (169)</td>
<td>98(169)</td>
<td>0.53</td>
</tr>
<tr>
<td>Ref.: action has to be taken</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Ref: is reference answer based on the stress-related glucocorticoid dose adjustment advice of the Department of Medicine, Division of Endocrinology, Radboud University Nijmegen Medical centre
<table>
<thead>
<tr>
<th></th>
<th>Baseline</th>
<th>Follow-up</th>
<th>p-value</th>
<th>McNemar</th>
</tr>
</thead>
<tbody>
<tr>
<td>the level of information concerning the treatment is considered satisfactory</td>
<td>68.6(172)</td>
<td>90.7(172)</td>
<td>&lt;0.0001</td>
<td></td>
</tr>
<tr>
<td>has the glucocorticoid instruction leaflet at home</td>
<td>57.7(170)</td>
<td>82.4(170)</td>
<td>&lt;0.0001</td>
<td></td>
</tr>
<tr>
<td>has ampoules of hydrocortisone at home</td>
<td>95.0(179)</td>
<td>96.1(179)</td>
<td>0.41</td>
<td></td>
</tr>
<tr>
<td>has practiced the intramuscular injection</td>
<td>57.4(179)</td>
<td>82.1(179)</td>
<td>&lt;0.0001</td>
<td></td>
</tr>
<tr>
<td>has a ‘Medicine passport’</td>
<td>74.7(178)</td>
<td>83.2(178)</td>
<td>0.007</td>
<td></td>
</tr>
<tr>
<td>has a so called ‘SOS medallion’</td>
<td>59.1(176)</td>
<td>69.3(176)</td>
<td>0.0007</td>
<td></td>
</tr>
</tbody>
</table>

Results are percentages(N) for yes answers
Figure 1. Flow chart study and participants

Invited patients
N=405

Participants
N=246

Non-participants
N=159

N=115

Baseline Questionnaire
(T= -2 weeks)
N=246

Glucocorticoid education meeting
(T=0)
N=246

N=63

Follow up Questionnaire
(T= +6 months)
N=183

N=44 ‘Responders’
Figure 2. Details on interventions by patients in hypothetical condition V: repeated vomiting or diarrhoea and a temperature below 38.0°C

P-values are representing the intervention ‘injection and phone contact’