The existential impact of starting corticosteroid treatment as symptom control in advanced metastatic cancer

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Treatment with corticosteroids often results in increased appetite, reduced nausea and improved well-being in patients with advanced metastatic cancer. Therefore, we have studied the existential impact of starting corticosteroid treatment as symptom control in this patient group using qualitative content analysis with both a descriptive and an interpretative focus. Ten patients were interviewed before and after 1 week of treatment with 4 mg betamethasone. Prior to treatment, patients reported distressing symptoms, deterioration and diminished autonomy, symbolising threat and death. Corticosteroid treatment produced symptom relief in the majority of the patients. They reported enhanced physical abilities and experienced feelings of a more normalized life and strengthened autonomy, symbolising health and hope. This transfer from threat to hope has important existential consequences in end-of-life care and should be addressed when communicating goals of treatment and care with the patient and family. Palliative Medicine (2009); 23: 165–170

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Introduction

Treatement with corticosteroids has many important symptom-relieving effects in patients with advanced cancer. There are several studies in palliative care settings showing significant but transient effects on poor appetite, strength and poor well-being as well as studies exploring the clinical use of corticosteroids in different countries.1–6 Despite the remarkable effects on disturbing symptoms in a palliative life-and-death situation, there are no studies exploring the existential impact of symptom relief achieved by corticosteroid treatment in the individual patient. What does increased appetite or reduced fatigue mean on a deeper level to patients with a short life expectancy?

Overall, the question of what we really achieve with symptom-relieving therapy has probably been overlooked in palliative care, and there are few studies exploring the deeper meaning of symptom relief in end-of-life care. Understanding patient’s perspectives when managing their needs has been shown to have an existential impact.7 Also, the consequences of poor symptom control with increased fear and disturbing thoughts have been reported in this patient group.8 The diagnosis of cancer, as well as the imminent death patients are facing in the terminal phase, has profound existential impact on both patients and families. Symptoms such as pain may even be perceived as a metaphor for death.9 The often seen crisis reaction and close-to-death related questions concerning bodily functions and symptom experiences have significant implications.10,11

The aim of the study was to explore the deeper meaning and implication of starting corticosteroid treatment as symptom control in patients with advanced metastatic cancer.

Patients and methods

The study was performed in a Swedish palliative care unit, with a capacity of 38 beds and 25 patients in advanced home care, located in a larger city. More than 90% of the patients in the setting have a cancer diagnosis, and the median survival from enrolment during 2005 was 14 days. Patients with advanced cancer to whom treatment with corticosteroids for symptom control was considered appropriate were suitable for inclusion. The decision to start corticosteroid treatment was made by the physician in charge outside the study. The physician
asked the patients’ permission for the researcher (first author) to contact them. Oral and written information about the study was given to the patients. Exclusion criteria in the present study were difficulties in speaking and understanding the Swedish language, cognitive impairment or expected survival less than a week.

A semistructured interview guide (Appendix A) was constructed by the authors and discussed with colleagues in the multiprofessional palliative care team at the unit. Each patient was interviewed twice by the first author; the day before starting corticosteroid treatment and after 1 week of treatment. Treatment during the study period consisted of 4 mg betamethasone (equipotent to dexamethasone) given orally, once daily. Ten patients with advanced cancer, six women and four men, were recruited during 1 year starting in autumn 2005. The patients were recruited in order to achieve variation in gender, age, level of education, cancer diagnosis and expected time of survival. The level of saturation of the recorded data was discussed between the first and last author throughout the study. Three patients had received corticosteroids as antiemetics in connection with earlier courses of chemotherapy. There was a predominance of gastrointestinal and gynaecological cancer, mean age was 74 years (range 49–88 years) and median survival from the day of the first interview was 24 days. One patient was still alive when the analysis was performed. Patient characteristics are presented in Table 1. One patient died within 1 week from the start of the treatment; in total 19 interviews were performed. Three patients were interviewed in their homes, the rest in the palliative care unit. The interviews lasted between 10 and 40 min. They were tape-recorded and subsequently transcribed verbatim by the first author. Demographic data and data on disease location, received treatment and concurrent illness were collected from the patient records.

Data were analysed using qualitative content analysis with no predetermined categories using both a manifest (descriptive) and a latent (interpretative) focus. The following stages of analysis were performed: 1) the material was read through repeatedly to obtain an overall impression and to identify themes relevant to the study. 2) The interviews were then reread carefully to identify significant text segments (meaning units) and to develop codes and preliminary categories. Until now the first and last authors worked independently while in the next step 3) all authors joined to obtain agreement on preliminary categories and to find the central component. The final categories were compared to avoid overlapping. Quotations were used to exemplify the categories. Coding and development of categories were mainly done by the first and last author. The second and third authors concentrated on the validation of the results. All authors have extensive experience of working in palliative care.

**Trustworthiness**

A dialogical validation was made with the patients, as similar questions were addressed several times during the interview, to ensure the patients’ genuine perception. A dialogical intersubjectivity was used, according to which the interviews were analysed separately by the first and last author and then compared for similarities and differences. The material was discussed until agreement was reached.

The study was approved by the local ethics committee.

**Results**

The manifest (descriptive) main categories identified during the analysis included 1) Problems at baseline, 2) Expectations before treatment and 3) Effects of the treatment (see Table 2). Moreover, a latent interpretative category ‘Existential implications’ emerged when the underlying meaning of the explicit statements was interpreted.

**Manifest focus**

**Problems at baseline – physical symptoms and anxiety**
Pain, nausea, fatigue, general anxiety and loss of appetite, weight or strength were common problems before corticosteroid treatment. Severe fatigue experienced as loss of physical strength, feebleness or overwhelming tiredness was reported. Three patients expressed a predominantly physical as opposed to mental tiredness.

### Table 1 Patient characteristics (n = 10)

<table>
<thead>
<tr>
<th>Localization of the cancer</th>
<th>Oncological treatment received or planned</th>
<th>Survival from the day of the first interview</th>
<th>Level of education</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pancreas</td>
<td>Chemotherapy</td>
<td>8 months</td>
<td>Elementary school</td>
</tr>
<tr>
<td>Colon</td>
<td>Radiotherapy</td>
<td>3–5 months</td>
<td>Secondary high school</td>
</tr>
<tr>
<td>Rectum</td>
<td>Surgery</td>
<td>1–2 months</td>
<td>University</td>
</tr>
<tr>
<td>Prostate</td>
<td>Hormonal</td>
<td>3–4 weeks</td>
<td>1</td>
</tr>
<tr>
<td>Ovary</td>
<td>None</td>
<td>2–3 weeks</td>
<td>1</td>
</tr>
<tr>
<td>Gynaecological UNS</td>
<td>None</td>
<td>1 week</td>
<td>Still alive</td>
</tr>
<tr>
<td>Cervix</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Palate</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
I feel completely out of strength. As if I only wanted to lie down and rest and close my eyes, all the time (Patient no. 7, first interview)

Expectations before treatment
Previous knowledge of corticosteroid treatment concerned mainly side effects such as swelling and bruises. Two patients commented its use in rheumatoid arthritis. However, patients also expressed belief in authority concerning the possible positive effects of corticosteroid treatment. Individual hope and expectations before treatment with corticosteroids focused on distinct objects such as better appetite, increased strength and hope for better physical abilities. Fulfilment of expectations would help the patients recapture activities of daily life that they had lost.

I hope it’ll make me feel better. So that I can move without feeling that I’m ready to drop when I’ve got out of the bed (Patient no. 10, first interview)

Effects of the treatment – general effects
As expected, patients reported improvement in symptoms such as poor appetite, nausea, fatigue and low mood. The positive effect came within 1–3 days and exceeded the expectations in three patients.

It has been good. It took about two and a half days before I begun to feel the appetite. Now I dream about food. It’s terrific (Patient no. 5, second interview)

Three patients reported equal improvement of physical and mental strength, whereas two patients experienced improved mental strength without improvement of physical strength. Patients experiencing a physical improvement became more active, for example, taking longer walks or taking part in housework.

It’s another strength in the body, except in the muscles of course. They’re not so good, but I can take longer walks without stopping (Patient no. 2, second interview)

Half of the patients reported side effects during the week of treatment and these consisted of hoarseness, flushing or dry mouth. One patient reported blurred vision.

Effects of the treatment – normalization
Patients experiencing positive effect of the treatment were able to participate in daily activities, could be physically more active, felt an increased need for associating with others and reported being recognized by visitors as having regained parts of their old personality.

When you’re getting started and get out, then you feel almost as ordinary. Like yesterday, I was in the garage working and searching for things (Patient no. 2, second interview)

Now they recognize me: “Aha, it’s old you, starting to get ill-tempered” (Patient no. 5, second interview)

Latent focus
Existential implications
The focus was on profound existential changes. In the first interview, it was common that the disease itself, progressing symptoms and loss of autonomy, implicated threat and impending death. Two patients being considered for palliative chemotherapy by the referring oncologists worried about not having enough strength to start the treatment. Chemotherapy symbolized a lifeline, and not being able to start treatment constituted a threat against life, increasing the fear of death.

Well, if you can’t start now (with chemotherapy), when will you be able to start, then it’ll be never once? It’s the only thing I’m thinking of (Patient no. 2, first interview)

Rapid deterioration with excessive weight loss contributed to anxiety and reinforced the threat. Also, reduced physical abilities with perceived diminished autonomy symbolised death.

Then I’m a little bit worried about everything going so damn fast... I’ve no strength. You can see I’ve no muscles left on my arms, it’s all gone. I’ve lost over 10 kilograms the last month (Patient no. 10, first interview)

I don’t feel well, I can’t do that, the way I have it now... Interviewer: You don’t feel well, but in what way? Patient: Because I’m in this situation (starts to weep) I don’t have the strength to do what I want...,
I almost have no strength... I’d like to do so much... but I can’t make it

(Patient no. 3, first interview)

I do not know... What can I hope for in this situation?
(Patient no. 9, first interview, when asked if he hoped for a change to occur)

Those patients who experienced positive effect of the corticosteroid treatment expressed feelings of more normalized life, which symbolised health. Less distressing symptoms combined with an improvement of strength and physical abilities rendered patients a perception of strengthened autonomy. This overall improvement helped the patients gain a more positive attitude towards their situation and enhanced the ability to set about working with things they had previously left behind. Enhanced abilities also meant increased expectations and the timeline was extended. Patients started to make plans not only for the near future but also for events in 6 months.

I’m more alert. I can go to the dining room to sit and eat, also laugh a little bit. I can take a short walk. Before, I didn’t have the strength to walk to the dining room, I became dizzy. Now I maybe have a little bit more strength, this means very much to me

(Patient no. 8, second interview)

The cortisone gave me a kick. It’s wonderful. Simply getting to a store, go shopping, just that... what a wonderful feeling to be able to get outside

(Patient no. 5, second interview)

The perceived improvement withdrew the immediate threat that aggravated symptoms had constituted before corticosteroid treatment. What this often rapid change from deterioration to improvement meant for the patients was interpreted as a reduced death threat, the return of hope and a revived link to life. Positive changes in even one single symptom could be interpreted as hope for an individual patient. Initial dramatic effects could be seen as magical.

To me it means very much that I have more strength. I want to be even stronger, but you can’t take it all at once

(Patient no. 8, second interview)

I feel fantastic. I can’t understand the difference in such a short time. It was like firing a new rocket

(Patient no. 10, second interview)

Two patients perceived no obvious effects of the treatment. They were both indifferent to the lack of effect and did not express any disappointments or feelings of lost hope in connection with the absence of improvement.

Discussion

This study has examined the existential impact of starting corticosteroid treatment as symptom control in advanced metastatic cancer. It is the first study to explore patient expectations and experiences of corticosteroid treatment in advanced cancer using a qualitative methodology. We have shown that symptom relief produced by corticosteroids has profound existential consequences in end-of-life care.

Relief of physical symptoms and treatment of psychological, social and existential/spiritual distress is often seen as four important cornerstones in palliative care. This division is pedagogical, but there is a danger of seeing them as standing alone, when they are in fact intimately linked together. Symptom relief renders existential consequences, as shown in the present study and this has probably been underestimated so far in palliative care literature.

Spiritual well-being has a central role in protecting against depression, hopelessness and desire for hastened death among terminally ill patients. The first step in an approach for the treatment of spiritual suffering outlined by Rousseau is control of physical symptoms. Also, in palliative care patients, symptom control has been shown to foster hope. Good symptom control creates hope that is not only limited to symptom control issues but also creates hope on a deeper level, as absence of symptoms is perceived as life and health. A progressive illness and increased symptoms are perceived as a threat, symbolising death.

In end-of-life care symptoms are often troublesome, but they may also stand as symbols of something. Aggravated symptoms, reduced strength and diminished physical abilities often reduce the perception of autonomy, which is perceived as an ultimate threat by the patient. Uncontrollable pain has been shown to hinder hope in palliative care patients. Corticosteroid treatment may reduce symptoms and increase strength, thereby strengthening autonomy and fostering hope. In everyday care, we are often not aware of the existential changes related to symptomatic improvement. Do we prescribe corticosteroids to primarily increase appetite and strength, or do we prescribe them to increase hope? Clinical experience shows that appetite is linked to hope and this is consistent with the observations in this study. Appetite symbolizes life, whereas loss of appetite is perceived as a threat and ultimately death. Loss of appetite is one of several symptoms that are common in patients with advanced cancer, and the study indicates that the same symbolisation can be applied to other symptoms in this patient group.

The interviews indicated that it was the change in itself towards improvement or deterioration rather than the
absolute level of symptom distress prior to treatment, which determined the patients’ experience of hope or threat in association with corticosteroid treatment.

The existential questions that these findings raise have significant impact on patients and relatives in end-of-life care and should be identified when communicating goals of treatment and care with the patient and family. Improved appetite and strength and less nausea can help the patients finish their lives in both a practical and a symbolic way. Corticosteroid treatment can, therefore, create respite in many patients and give them possibilities to finish “unfinished business”. When prescribing corticosteroids for symptom control in advanced cancer, the physician should inform the patient about the chances for improvement, although earlier studies show that this improvement often is of short duration. This transient improvement may be reflected in an experience of more normalized life, as shown in the present study, and could be seen as a basis for discussion around goals for the remaining life. Given a respite with a period of improved condition – what is important to accomplish? What is important to conclude?

Two out of ten patients in the present study perceived no discernible effects of the treatment. They did not express feelings of disappointment or lost hope in association with the absent effect. Poor expectations prior to the treatment probably contributed to their indifference.

There are several limitations to the present study. The sample was 10 patients, living in an urban area, with predominantly gastrointestinal and gynaecological cancer. Most patients presented a similar picture indicating a relative saturation of the data. The level of saturation was discussed continuously and was considered to be satisfactory after 10 patients, as there was little contribution of new data that added to the research question. However, it cannot be out ruled that an increased number of patients would have given further insight. All patients presented with multiple symptoms, and other symptom relieving interventions performed during the week of corticosteroid treatment might have influenced the perceived improvements. However, much effort was put into the interviews to discern the effects of corticosteroid treatment from other concurrent therapies, and patients experiencing positive effect were very clear about the connection with corticosteroid therapy. Patients reported positive expectations on the treatment and placebo effects cannot be ruled out. However, earlier studies show a significant effect of corticosteroid therapy in a majority of patients with advanced cancer. One patient died before the second interview and was not evaluated by the researcher or the nursing staff concerning effect of the treatment.

Side effects of corticosteroids are common, and hoarseness, flushing, dry mouth or blurred vision was reported. Mental disturbances like depression and euphoria as well as initial insomnia are common. The absence of these side effects in this study may be due to the small patient material and short follow-up. Continuing corticosteroid therapy often leads to more disabling side effects like proximal myopathy, Cushingoid features and fragile skin. These negative effects, together with potentially diminishing beneficial effects during continuous corticosteroid treatment, could have negative existential impact on patients. Also, if initial symptom relieving effects are only of short duration, there is a risk of negative existential impact replacing the initial positive outcome. At the end-of-life when patients no longer are able to swallow the medication, it is often stopped. Having experienced an initial positive effect of the corticosteroids, it can be difficult for patients and their families to stop the treatment. Future studies with similar design should have a longer follow-up, preferably during the whole duration of steroid use, exploring possible changes in existential impact. These studies could also examine to what degree symptom control, in general, has an existential impact in the palliative care population.

In conclusion, we have shown that starting treatment with corticosteroids for symptom control in patients with advanced metastatic cancer can have profound existential consequences. Reduced symptoms contribute to feelings of normalized life, symbolizing hope. This should be addressed when communicating goals of treatment and care with the patient and family.

References


**Appendix A**

**Interview guide (adapted to suite the first or the second interview)**

How do you feel at this moment?
What are your current physical symptoms?
What are your current psychical symptoms?
What is your view on your present well-being and quality of life?
What is your view about your current life situation?
Your expectations on the treatment with corticosteroids?
Your previous knowledge about corticosteroids?
What effects have you experienced from the treatment with corticosteroids?
What side effects have you experienced?
What is your overall impression of the corticosteroid treatment?