

Muath Alduhishy

DipHealthSc BBioMedSc MBBS, Resident Medical Officer, Rockhampton Hospital, The University of Queensland, QLD, Australia

A proposed steroid card model for palliative care patients

Abstract

Background. Poor medication compliance and control may diminish the effectiveness of the prescribed therapy and might threaten the patient's health. It is a substantial issue in palliative care as almost one-third of patients fail to conform to their therapeutic regimens. Non-compliance may lead to more admissions, longer stay at hospital and more short-term and long-term morbidity and mortality.

Purpose. Tools have to be implemented to limit non-compliance and ensure that patients are able, with encouragement and supervision, to monitor their treatment progress. Medication card is an excellent candidate, since it retains the essential information of the patient, doctor and the prescribed drug, and it also provides convenience, as patients are able to check their progress in real-time, and keep an eye on potential side effects and complications. This paper describes a model created of patient-version of steroids medication card that fulfill the abovementioned goal and provide this service to the palliative care patients.

Methods. The research was guided and supervised by palliative care specialists and nurses, and I approached multiple patients to calibrate the language and structure for simplicity and clarity. Furthermore, I reviewed official medication card forms produced by major hospices in order to configure the appropriate composition and format of the card. This work is expected to facilitate control and monitoring of steroid regimens palliative care settings.

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Key words: medications, steroids, palliative care, patient safety

Introduction

Palliative care is the branch of medicine that specialises in managing people with serious and terminal illnesses, and their families, by providing relief from physical and psychological symptoms, primarily pain and stress [1]. The main objective of care is to improve their quality of life and preserve their dignity as much as possible [2]. During therapeutic management, palliative care practitioners prescribe a myriad of medications that are known to have serious side effects, such as opioids, steroids and anticonvulsants. It is worth noting that palliative care patients typically have advanced diseases and their health

conditions are usually much poorer than the majority of patients. Consequently, monitoring such clients for potential adverse effects and complications as well as keeping a tight and attentive control on the dosage and compliance are imperative and essential role in being a palliative care practitioner. It is evidently not sufficient to rely only on observable physical and mental deviations or counting solely on the patient's self-reporting. That is because side effects might not be plainly obvious to palliative care practitioners and patients alike, and on the other hand, patients are certainly prone to forget and neglect such changes, or might interpret them as an expected progression of the disease. Therefore, a tool devised to ensure

Corresponding address: Muath Alduhishy

4/15 Parkside Place, Norman Gardens

QLD 4701 Australia

tel: +61412203139

e-mail: dr.alduhishy@gmail.com



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patients and practitioners' attention and vigilance towards adverse effect and complications has to be implemented in such settings. Medication cards, that contain essential information about the patient and the prescribed drug, can be very helpful here, especially for those on a long-term course of potentially harmful classes of drugs, which steroids is an obvious example in the domain of palliative care [3]. Steroids or corticosteroids are used commonly in palliative care to alleviate specific and non-specific symptoms related to diseases like advanced malignancies. A few types of corticosteroids are used in palliative care, namely Dexamethasone and Prednisolone, and both have variable efficacy. The indications for corticosteroids use include, for example, spinal cord compression and elevated intracranial pressure as well as pain, nausea and malaise [4]. The widespread and prolonged use of steroids has inevitably led to an increase in the prevalence and impact of its side effects, both major and minor. These include disruption of innate hormone secretion in the hypothalamus-pituitary-adrenal (HPA) axis, as well as sodium and water retention, immunosuppression, edema in the extremities, psychological changes, hypertension, hyperglycemia, and skin changes. Furthermore, corticosteroids have contraindications with numerous drugs that are prescribed frequently, such as particular classes of antivirals and antibiotics. They should also be avoided, or at least reconsidered, in a number of medical conditions, such as diabetes mellitus and active infection, as they will most likely aggravate the disease symptoms and signs in the affected person [5].

Following the aforementioned facts, I started working on a steroid medication card model while wor-

king at the palliative care services in the Royal Brisbane Hospital. This card has to be written in lay-language, as it will be chiefly directed to and managed by the patients, and should contain their personal information, exhaustive details about the prescribed drug, and the prescribing doctor's contact information. I worked under the supervision and advice of the palliative care specialists and nurses. They offered me a considerable help to generate an appropriate structure and plan starting from the initial scheme as seen in the appendix (Fig.1).

Material and methods

The steroid medication card that was devised here has been initially inspired from a doctor-oriented Steroid Proforma acquired from the Princess Alexandra hospital, which was produced in 2008 by a coalition of hospices and palliative care providers in the United Kingdom (Fig. 2) and also a Steroid Replacement handout produced by the Imperial College Healthcare NHS Trust (Fig. 3). Next, as the project progressed, I had multiple meetings with the director of the palliative care services at the Royal Brisbane hospital Dr. Carol Douglas, and the palliative care specialist Dr. Alison Kearney, as well as discussions with the rest of the team members, including palliative care nurses and medical trainees. I also consulted with some of the patients whom the services oversee to gauge the clarity and simplicity of the language and structure. Unlike the two documents that were mentioned in the beginning of this section, which have markedly descriptive and instructive technical structure, my design is much more 'layman-friendly'

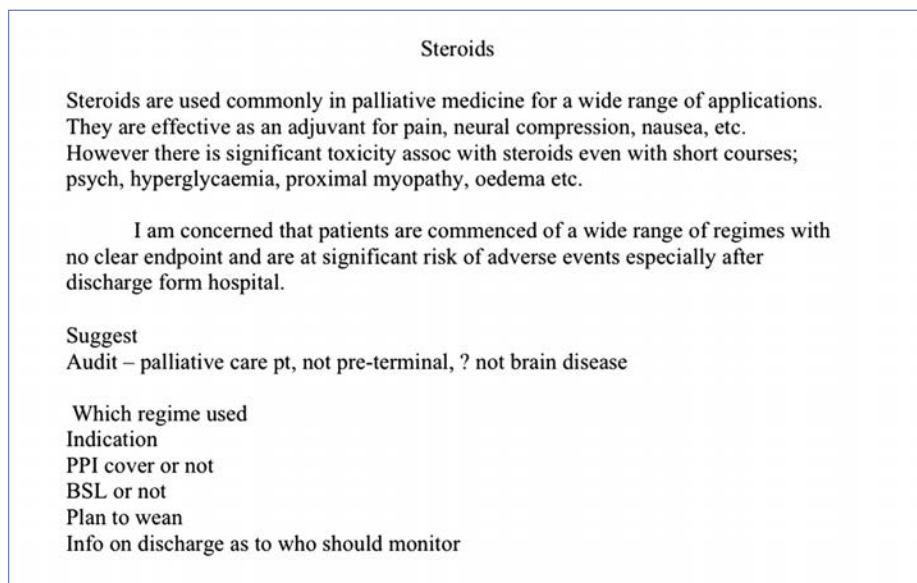


Figure 1. The initial scheme of the project

Figure 2. Steroid Proforma produced by the Princess Alice Hospice, Harris Hospice Care, Guy’s and St Thomas’s Foundation and St. Christopher’s Hospice in the United Kingdom

as it was aimed to patients so they can participate in the drug monitoring process. At first, the initial draft (Fig. 4) has the title “Steroid Card for Palliative Care”, to elucidate the intended purpose, and the caveat “Complete once for each course”. It consists of one page that has spaces to be filled pertaining to the prescribed drug specifics, namely its type, starting dosage, frequency, route, indications and whether it has been used before or not. In addition, a space was left for the course plan including when to wean, and a section illustrating the main contraindicated drugs and conditions has been added. The card also asks technical questions directed to the doctor about further clinical details and precautions. Later on, the following issues have been highlighted: 1) Dexamethasone and Prednisolone are the only corticosteroids available for palliative care patients in the hospital. 2) Drug frequency should be left as blank to give more freedom. 3) A space should be provided for the prescribing doctor information. 4) Clinical instructions should be avoided since it is directed to patients not doctors. 5) Writing spaces are too small and thus must be expanded. 6) The major side effects should be included.

Unsurprisingly, when I consulted with a number of palliative care patients they found the first draft to be difficult to read and use.

Next, the steroid card was amended and improved based on the previous suggestions along with a redesigned and enhanced layout. Accordingly, with the assistance of the literature, the major side effects, specifically those that present to patients as observable symptoms, are highlighted in a simple language [5, 6]. The idea is to alert patients so they can contact their doctors when such symptoms manifest. Furthermore, a review table was added on the back of the paper to record the details of every drug review. It encompasses the date of review, response, toxicity, new dose, date of the next review and the reviewing doctor signature. A warning was also annexed to emphasise on patients not to stop taking steroids without consulting their doctors.

Discussion

The final work was completed as pictured in Figure 5. Given the importance of the subject, the design’s schema and language were purposefully simplistic in

ICE
Imperial Centre
for Endocrinology

Patient Name:

Address:

Telephone No:

Consultant Contact Details:

GP Contact Details:

In Case of Emergency Contact Details:

www.imperialendo.com

ICE Imperial College Healthcare **NHS**
Imperial Centre NHS Trust
for Endocrinology

**I am a patient on
STEROID REPLACEMENT**

This must not be stopped and in the case of emergency may need to be increased

Full details are available from the hospital or general practitioners shown overleaf.

My steroid replacement is:

Medication	Dose	Frequency

For Condition;.....

If you have any questions about your medicines please contact your doctor, pharmacist or specialist nurse.

Pharmacy Drug information
Open between 9.15a.m – 5.00p.m.
Monday to Friday

<small>Charing Cross Hospital</small>	<small>020 331 11703</small>
<small>Hammermith Hospital</small>	<small>020 331 33915</small>
<small>St Mary's Hospital</small>	<small>020 331 21203</small>

ICE
Imperial Centre
for Endocrinology

INSTRUCTIONS

1. DO **NOT** STOP taking your steroid replacement
2. In case of feverish illness, accident, surgery, diarrhoea or vomiting your steroid replacement **MUST** be continued. You may require a larger dose through these types of illness. See patient information on www.imperialendo.com
3. Always carry this card.
4. Show this card to any healthcare professional who gives you treatment.

Information in case of emergency

- 100mg hydrocortisone by intramuscular injection and seek urgent medical help.
- Emergency intravenous fluids and ongoing steroid replacement will be started by your healthcare professionals.

NOTE: use only hydrocortisone sodium phosphate or hydrocortisone sodium succinate. DO NOT use hydrocortisone acetate due to its slow release microcrystalline formulation.

Other Medications:

Medication	Dose	Frequency

Other Conditions:

- 1.
- 2.
- 3.
- 4.
- 5.
- 6.

Figure 3. Steroid Replacement handout produced by the Imperial College Healthcare NHS Trust

order to be visually clear and undistracting. The medication card consists of two pages so it can be printed into a one double-sided sheet of paper making it convenient and easier to carry around. There is a designated space in the upper left corner of the first page to affix the patient label, which has their basic information. However, if the label was not available, the patient can fill his or her own information, specifically the name, number, dates of birth and address. Next, the right side of the first half of the page is assigned to the essential drug details; starting date, type, initial dose, frequency per day, where it was started and the prescribing doctor's contact details. Then, a large table was drawn with this warning on top of it "DON'T STOP taking steroids

without consulting with your doctor". Underneath it, there is a space left to write down the indications for taking the medication, and another space to answer the question "Have you used Steroids before?". If the answer was yes, then more questions have to be answered: Why? What type? For how long? and How was the response?. Next, the drug course details have to be written including the date of first review, duration of course and indications for stopping and weaning. Afterward, lists of the main medical conditions and medications that are contraindicated with steroids, and also the major symptoms of adverse effects were charted with the declaration: Please inform your doctor if you are having/taking/experiencing the listed items. At

FOR PATIENT INFORMATION **DRAFT** (1)

Steroid Card for Palliative Care

Complete once for each course

Starting Date:/..../..

Medication: Dexamethasone
 Prednisolone
 Prednisolone - N/A
 Hydrocortisone

Initial Dose: ...mg *see over*

Frequency: Morning Twice Thrice
 Every ... hours

Route: PO *see over*

Started By: Hospital Hospice GP *Belinda Go Suire*

Patient Label: *12345*
07 3646 6138

Need order for contact numbers.
Dr. ...

for medical staff
pharmacy

Indication(s):

Have you used Steroids before? Yes No
 If yes, please give details (eg, type, dose, duration):

Do you have any of these conditions?
 Diabetes Yes* No
 *Stop Ins. +/- reduce steroids dose
 Heart Failure Yes* No
 *Monitor sodium
 Kidney Failure Yes* No
 *Monitor steroids serum level +/- adjust dose
 Liver Failure Yes* No
 *Use Prednisolone instead of Prednisone
 Infection Yes* No
 *Optimize antibiotic +/- alter steroids
 Previous Psychosis Yes* No
 *Add Haloperidol as cover +/- increase steroids dose

Are you taking any of these medications?
 NSAIDs/Aspirin Yes* No
 *Review/stop NSAID +/- initiate PPI as cover
 Phenytoin Yes* No
 *Review drug choice +/- increase steroids dose
 Carbamazepine Yes* No
 *Review drug choice +/- increase steroids dose
 Oral contraceptives Yes* No
 *Consider stopping OCP +/- decrease steroids dose
 Antacids Yes* No
 *Separate steroids intake from antacids by +2 hours
 Antibiotics/Antivirals Yes* No
 *Consider changing drug +/- decrease steroids dose

Are there any other questions or any initial actions taken?
 Plan:

Details (eg, when to stop):

Are there any other clinical details?
 Psychiatric: Yes No
 Date of first review:/..../.. Duration of course:

Who will monitor after discharge? Hospital Hospice GP
Pall Care Service

Planned term of course
Do not stop taking steroids without speaking to Dr.
Please inform your doctor if you are taking the following medication:

Please make for symptoms, anxiety, unstable blood sugar, vision, headache, poor sleep, asthma

For HEALTH PRO MONITORING

DATE of review *TOXICITY* *PROPOSED DOSE ADJUSTMENT* *NEXT REVIEW*

Figure 4. First draft of the steroid card with the proposed comments and notes

Steroid Card for Palliative Care

Complete once for each course

Starting Date:/..../..

Medication: Dexamethasone
 Prednisolone

Initial Dose: ...mg

Frequency per day:

Started By: Hospital GP Palliative Care service

Name of Doctor: _____ Name of Center/Service: _____

Contact Details: _____

***DON'T STOP taking steroids without consulting with your doctor**

Indication(s):

Have you used Steroids before? Yes, please give details No
 Why?
 What type?
 For how long?
 How was the response?

Plan: Date of first review:/..../..
 Duration of course:
 Indications for stopping:
 Other Details:

***Please inform your doctor if you have any of the following conditions:**
 Diabetes Heart, Kidney, or Liver Failure Infection Psychiatric condition

***Please inform your doctor if you are taking any of the following medications:**
 Non-steroidal anti-inflammatory drugs, such as Aspirin, Ibuprofen, and Naproxen
 Oral contraceptives Anticoagulants Antacids Antibiotics Antivirals

***Please inform your doctor if you start having these symptoms after taking steroids:**

Ankle swelling	Agitation	Sore mouth
Vision problems	Poor sleep	Muscle weakness

Who will monitor after discharge? Name of Doctor: _____
 Name of Center/Service: _____
 Contact Details: _____

Please Complete One Row For Each Review

Date	Response	Toxicity	New Dose	Next Review	Doctor Sign.	Notes
..../..../..			mg To mg/..../..		
..../..../..			mg To mg/..../..		
..../..../..			mg To mg/..../..		
..../..../..			mg To mg/..../..		
..../..../..			mg To mg/..../..		
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*Response: X None; ✓ Minimal; ✓✓ Good; ✓✓✓ Complete
 *Toxicity: -None; - Mild; - Moderate; - Severe

Figure 5. The final form of the steroid card for palliative care patients

the end of the first page, the name of doctor who will monitor the therapy regimen after discharge has to be recorded with their contact details. On the second page that resides in the backside, a large segmented table is drawn to record the progress of therapy by documenting each drug review including the date, response, toxicity, adjusted dose, date of the next review, and the doctor signature.

Conclusions

To conclude, the product of the project conducted here is a steroid card developed under the supervision of experienced palliative care specialists as well as lay-people's validation of the clarity of its language and structure. It encompasses the necessary information to verify the identity of the patient and their doctor along with thorough details of the medication and its therapeutic course. The steroid card offers an excellent tool to monitor patients' compliance and detect if they start to develop any of the major side effects or complications. However, this is not the end of the line. The next step is to conduct a pilot study on a set of patients, while using another set who did not receive this card as controls, and see if this steroid card aids significantly in the patient adherence to the therapy regimen and whether it provides better control and vigilance to side effects and complications. The outcome of the study will confirm the value of such a tool, and it will guide

future decision on using medication cards in palliative care, or even other branches of medical practice.

Conflict of interest

None of the material has been published previously, is under consideration, or has been accepted for publication elsewhere. All persons listed as authors have read and given approval for the submission of the manuscript.

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