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.

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
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 working 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’

<table>
<thead>
<tr>
<th>Steroids</th>
</tr>
</thead>
<tbody>
<tr>
<td>Steroids are used commonly in palliative medicine for a wide range of applications. They are effective as an adjuvant for pain, neural compression, nausea, etc. However there is significant toxicity assoc with steroids even with short courses; psych, hyperglycaemia, proximal myopathy, oedema etc.</td>
</tr>
<tr>
<td>I am concerned that patients are commenced of a wide range of regimes with no clear endpoint and are at significant risk of adverse events especially after discharge from hospital.</td>
</tr>
<tr>
<td>Suggest Audit – palliative care pt, not pre-terminal, ( ? ) not brain disease</td>
</tr>
<tr>
<td>Which regime used Indication PPI cover or not BSL or not Plan to wean Info on discharge as to who should monitor</td>
</tr>
</tbody>
</table>

Figure 1. The initial scheme of the project
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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

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
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.

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

<table>
<thead>
<tr>
<th>Medication</th>
<th>Dose</th>
<th>Frequency</th>
</tr>
</thead>
<tbody>
<tr>
<td>Steroids</td>
<td>1mg</td>
<td>once daily</td>
</tr>
</tbody>
</table>

For Condition: ____________________________

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

Emergency Drug Information
Open between 9am - 5.59pm, Monday to Friday
Cheyne Chase Hospital
University Hospital of Southend
St Mary’s Hospital
033 303 13769
033 303 99918
033 303 21240

INSTRUCTIONS
1. DO NOT STOP taking your steroid replacement
2. In case of fever, flu, 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 succinate. DO NOT use hydrocortisone succinate due to its slow-release microcrystalline formulation.
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Figure 4. First draft of the steroid card with the proposed comments and notes

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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Reference