Feasibility Study of a Web Application for Self-Report of Anticancer Treatment Toxicities

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Abstract. Collection of collateral effects related to toxicities suffered by patients being exposed to anticancer treatments is of crucial importance in clinical practice but also in oncological research. The present paper describes a web application called PaTOS for self-report of anticancer therapy toxicities, and its evaluation in a preliminary interface analysis and then in a feasibility study.

Keywords. Web 2.0 applications, home-based eHealth

1. Introduction

Collection of collateral effects related to toxicities suffered by patients being exposed to anticancer treatments is of crucial importance in clinical practice but also in oncological research.

The usual way of recording such symptoms is by means of a doctor-patient dialogue carried out during the pre-therapy visit. However, discrepancies outcropped when traditional modalities in collecting information regarding toxicities suffered by patients being exposed to anticancer treatments have been compared to direct self-reports [1].

Reasons for such differences are due to the whole chain intercurring between patient experience of the symptom and recorded data usage [2]: clinician interpretation of symptom during interview, written representation of symptom, eventually further interpretation of written symptom by a research assistant and its translation as data written in some research database are all steps that might be subject to error.

The basic idea underlying the approach discussed in the present paper is to shorten that data coding chain, to reduce possible error sources during data registration. This means giving the patient some more responsibility and power in reporting his/her symptoms, according to those principles recently called “Medicine 2.0” [3] after the name “Web 2.0”.

One way of interpreting such principles into the online healthcare framework is that of a larger consumer involvement into production and registration of health data.
regarding him/herself. Access to their own data has been recognised as useful since
eighties [4], and more recently Internet health records have been indicated as a
technical facilitators for that [5]. In fact, after pioneeristic experiences of some years
ago [6–9], some commercial proposal is now gaining momentum, like Google Health
and Microsoft HealthVault, that gives consumers a way for recording their health data
and then giving online access to healthcare professionals.

Starting from these principles, we hypothesized that a Web 2.0 application could
be an accurate and reliable tool to directly record toxicity data by the patient, to help in
reducing recording and interpretation errors.

Some previous experience is available in other clinical fields that supports this
kind of application: in diabetes management [10], asthma monitoring [11], heart failure
[12]. In oncology, a notable experience has been made by Basch et al. [2] that also
suggested attention to reminders and clinician feedback.

The present paper describes a web application called PaTOS for self-report of
anticancer therapy toxicities, and its evaluation in a preliminary interface analysis and
then in a feasibility study.

2. Methods

2.1. Data Collection

In the analysis phase conducted with joint meetings between computer science experts
and oncologists a number of specifications have been developed that included also a
specification of the data to be collected. Patients were supposed to provide self-
collected data at least once a week, with the possibility to contribute more than one
time a week if they wanted to. Symptoms were to be reported day by day, if any.

To code symptoms, it has been decided that a simplified, patient-adapted definition
of type and NCI-CTCAE grade [13] of the 15 commonest toxicities has to be used,
together with the possibility of reporting previously undefined symptoms by means of a
free text area.

Patients had control visits every two weeks, where they reported symptoms in the
traditional way, for comparison with self-registered ones.

2.2. The Web Application

To support data collection, a web application called PaTOS has been developed using
Java 2 Enterprise Edition and MySQL as a database server that fulfills specifications
coming from domain experts.

Using PaTOS through home Web access, each patient can access using a personal
username and password and compile a daily report of the affecting toxicities by
choosing and grading any of them from the user interface. If too much time has passed
since the last patient report, PaTOS will send the doctors a communication about the
missing data. This decision also takes into account suggestions about reminders and
clinician feedback discussed in [2].

Physicians access to a specific part of the site where they can perform managing
operations on patients’ data, as inserting or updating database information and visualize
flowsheets of patient toxicities by means of graphing functions.
To help in application evaluation, a log subsystem has been implemented to record every action carried out by users.

To verify the usability of the developed application, a first preliminary test aimed at interface analysis has been carried out before adopting it in a real world feasibility study. PaTOS usability test involved 8 non patient users, chosen among people with oncology knowledge, to which two simulated toxicity scenarios have been proposed for coding into the system [14]. This first test allowed to recognise some minor misbehaviour in the interface, mainly related to unclear day selection, that lead to a redesign of some parts of the application, together with a general esthetical enhancement to make it more user friendly.

After that, the application has been considered ready for a feasibility study on oncological patients. Figure 1 shows two snapshots of the application.

![Figure 1. Two PaTOS snapshots](image)

For the first test and feasibility study the approach to privacy and security issues has been simplified: no personal data are inserted into the system, and the patient accesses the application by means of an anonymous code that is related to his/her data only on an independent archive (actually, paper-based).

2.3. Subjects

Eligible patient were consecutively chosen among those starting an antitumoral treatment in the Department of Oncology of the University Hospital of Udine, Italy. Of 56 contacted patients, 30 accepted and signed an informed consent. Patients were representative of various tumoral diseases.

3. Results

28 out of 30 patients were observed during 10 weeks, corresponding to one (8 patients) or two (20 patients) completed treatment cycles.
In the observation period, users did a total of 231 accesses, plus a number of failed access attempts (due mainly to wrong password). 193 accesses were fully completed, resulting in the registration of symptoms. Among the uncompleted accesses, some were due to a missed final step in registration, caused by a click towards password modification.

Apart from some minor pitfall, the web application appeared surprisingly quick to learn and use. Figure 2 shows a graph of average time per patient, adjusted per number of symptoms reported. Learning time was also evaluated: between the first and sixth input session, time decreased of about 50% on average.

![Figure 2. Adjusted average input time in minutes per patient](image)

Only 18 out of 193 input sessions were reported to be carried out by family instead that directly by the patient.

At the end of study time, patients inserted a total of 1,870 symptoms observations (average: 69 per patient, 1.5 per day).

Self-reported data were compared with data registered during control visits by means of K-statistics. Although the statistical method revealed not fully adequate due to the large amount of symptoms non graded, comparison revealed a greater precision in reporting at home than during the visit, possibly due to the almost realtime registration after episodes, and in particular for low intensity symptoms, which are easier to forget, although they help oncologists to better personalize treatment.

Of 1,870 observations, 851 were related to toxicities of degree 1, 652 of degree 2, 254 of degree 3. The free text box available at the end of the questionnaire has been used 44 times, only two for a toxicity not present in the list, the other for communications to the oncologist.

Self-reported symptoms distribution was compatible with frequencies reported in literature. In fact, the most selected toxicity was tiredness (408 observations, 22% of total), the least one was fever (13 observations, 0.7% of total).

4. Discussion

While only a prototype, the proposed system appeared to be a good way to collect anticancer therapy toxicity information directly by the patient, overcoming problems
related to memory, which usually makes low degree symptoms be unreported to the oncologist. Agreement between self-reported data and data communicated to the oncologist was good for the most objective observations, less for observations where doctor and patient perceptions may differ.

Time needed for input was lower than expected, with about 6 minutes per session on average. Not all patients complied with the request for at least one input session a week, although some of them accessed the system more often, possibly during or after symptoms.

Although the sample involved in this feasibility study was small, the results have been convincing, and now a clinical trial is starting, with a larger user base. At the same time, a technical solution is being studied to embed the system into the regional citizen portal that provides secure access authenticated by means of a smart card. On the physician side, currently an oncologic patient record exists where doctors record toxicities, but that is not yet linked to the PaTOS application. After a more formal clinical trial however PaTOS will be connected to the patient record to avoid data entry duplication.

References


