A platform to study the quality of life in oncology patients

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Abstract: The perception that an individual holds about his place in life, which depends upon his culture and values, defines this individual’s quality of life (QoL). When applied in a health context, this known as: health-related quality of life (HRQoL). The assessment of HRQoL is a medical goal; it is used in clinical research, medical practice, health-related economic studies and in planning health management measures and strategies. Obtaining a patient self-assessment with QoL measuring instruments on the platform developed in this project, through friendly software, easy for the user to adapt to, aids the study, promotes the creation of databases, and accelerates its statistical treatment. The possibility of graphically representing results that physician needs to analyse, immediately after the answer collection, makes this assessment a diagnosis instrument ready to be used routinely in clinical practice.

Keywords: oncologic patients; health-related quality of life; HRQoL; knowledge management systems; KMS; human-computer interaction.

1 Introduction

The concept of ‘quality of life – QoL’ is used in different contexts and situations, reaching practically all sectors of society. The perception an individual holds about his place in life, which depends upon his culture and values, defines this individual’s quality of life (QoL). When applied in a health context, this is known as: health-related quality of life (HRQoL) (Pimentel, 2003). Nowadays, indicators of HRQoL are used in health management strategies. Managers, economists, political analysts and pharmaceutical companies use QoL measures from the World Health Organization (WHO) in some of their departments (Schottenfeld and Fraumeni, 1996). Today, HRQoL is a medical goal, being used in epidemiological studies, clinical essays, medical practice, health-related economic studies, and in planning and comparing measures and strategies (Stewart and Kleihues, 2003).

Preliminary studies indicate that the implementation of a patient HRQoL assessment in Portugal is challenged and questioned for several factors involving health institutions, health professionals and patients (Rodrigues, 1998). The reasons include: a lack of familiarity with relevant studies in this area; the absence of sensitivity; lack of time; reluctance in accepting that the patient’s perceptions regarding their own outcomes are as important as the physicians (Caçador et al., 2001); difficulty in quantifying subjective parameters; difficulty in converting tactic knowledge in explicit knowledge; inexistence of friendly computer-based applications; inexistence of healthcare service infrastructures that enable a routine HRQoL assessment.
The purpose of this project is to allow the physician to use patient’s QoL measurements as clinical decision support elements. A timely knowledge of the patient’s QoL-related elements constitutes another factor that may, in certain circumstances, contribute to a better decision making. On the other hand, a systematic patient QoL data collection allows the standardisation of this information and to infer therapeutic strategies for a specific patient. In other words, in the presence of several therapeutic strategies, this can help the physician by giving him clues about the patient’s future QoL according to applied medical acts.

In the present paper, we intend to demonstrate the importance of HRQoL assessment in oncologic patients, and the relevance of knowledge management systems (KMS) as decision making aids. We analyse this problem and show the results obtained with a platform developed for the self-evaluation questionnaire that measures patients QoL in this project and collect clinical information in order to infer about the patient future QoL through the cross between the QoL measure and the several treatments used in the patients.

2 Evaluation of HRQoL in oncologic patients

Malignant tumours are the second leading cause of death in Portugal. Their relevance as a morbidity and mortality factor is growing and their social impact is being recognised (Pimentel, 2003). The global weight of oncologic disease is growing, given the economic and social costs involved in the prevention, treatment and rehabilitation of this disease (Hecker et al., 2002).

Research methods used in oncology enable us to analyse the oncologic process in its physiopathologic and clinical aspects, penetrating wide domains like the psychological, social, economic and organisational domains (Pimentel, 2003). Epidemiology and statistics are significant aspects of this study, since oncologic care can only be programmed based in safe databases (IPO, 1996). Assessing the implementation of these diseases in our community helps to recognise the global impact of tumours and to evaluate the effectiveness of the adopted control measures (Schottenfeld and Fraumeni, 1996).

The time where therapeutic decisions were not discussed with the patient and the family, and treatment options were not even considered, has long since passed. Oncologic patients were frequently not informed of their diagnosis after their families were. This reality has changed and, today, patients participate, or should participate, in the several stages of their treatment (Pimentel, 2003).

In fact, patients motivated to participate in their treatment and rehabilitation plan often show a better QoL, and should therefore be involved in the strategies developed to fight their disease. Furthermore, evidence shows that a global patient QoL optimisation can lead to a higher survival rate and to a higher QoL (Pimentel, 2003).

Promoting the integration of QoL assessment in clinical practice can result in the optimisation of infrastructures and methods capable of improving patients QoL (Varzim et al., 2001). A validated, safe and scientifically-based measuring instrument must be made available in a simple format, understood both by the patient and the physician, and it should be completed in less than ten minutes (Colli and Colli, 2006).

Although being a subjective concept, HRQoL is quantified objectively and does not merely represent the inexistence of disease (Pinheiro et al., 2002). The multidimensional...
conception of HRQoL comprises a wide range of physical, psychological, functional, emotional and social variables, and these, as a whole, define welfare (Pillai et al., 1999). These domains vary individually according to religion and beliefs, culture, expectations, perceptions, education, knowledge, etc. (Pillai et al., 1999).

Table 1 represents schematically some of the HRQoL dimensions and elements, proposed by the WHO (Meneses, 2005):

<table>
<thead>
<tr>
<th>Physical health</th>
<th>Psychological</th>
<th>Social relationships</th>
<th>Relationship with the environment</th>
</tr>
</thead>
<tbody>
<tr>
<td>Activities</td>
<td>Self-esteem</td>
<td>Sexual activity</td>
<td>Economy</td>
</tr>
<tr>
<td>Pain</td>
<td>Self-esteem</td>
<td>Social support</td>
<td>Information</td>
</tr>
<tr>
<td>Dyspnea</td>
<td>Body image</td>
<td>Family</td>
<td>Means of transportation</td>
</tr>
<tr>
<td>Mobility</td>
<td>Thoughts</td>
<td>Personal relationships</td>
<td>Security</td>
</tr>
<tr>
<td>Medication</td>
<td>Negative feelings</td>
<td></td>
<td>Services</td>
</tr>
<tr>
<td>Insomnia</td>
<td>Positive feelings</td>
<td></td>
<td>Free time</td>
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</tbody>
</table>

3 KMS in routine HRQoL assessment

Preliminary studies on oncologic patients conclude that the use of an adequate software for the HRQoL assessment, data collection and processing, allows us to obtain selfanswered questionnaires from patients, an automatic quotation of these questionnaires, the creation of a database and the statistic analysis of the results, favouring a routine HRQoL clinical assessment (Silveira, 2007).

Moreover, the graphical representation of results enables a fast patient HRQoL assessment by the physician, and this evaluation becomes a diagnosis instrument to be used in routine clinical practice (Silveira, 2007).

HRQoL assessment is dynamic and requires periodic re-evaluations (Sobrinho et al., 2001), it should be done objectively and quantitatively on a routine basis. And to do so, the selection of a measuring instrument with good psychometric characteristics, easy to administrate and to quantify, that does not increase the appointment time and with a multidimensional character is most important. It must be answered and quoted before appointments. The results should remain confidential and anonymous, and when graphically represented, they allow an easy reading of the patient’s self-perception. Thus, HRQoL assessment becomes a diagnosis instrument that identifies patient’s problems, highlights certain signs and symptoms that could otherwise go unnoticed, improves the physician-patient communication and assists therapeutic decisions; in other words, it renders the appointments easier. By analogy, the physician can evaluate the evolution of his patient’s state by comparing two or more assessments obtained in different periods (Bottomleya et al., 2002).

However, a routine assessment implies the design of a new appointment protocol. The analysis and specification of the information system requirements, as well as the specification of necessary activities for the process, defines the knowledge management system which supports the clinical decision aid system, based on the HRQoL assessment.
4 Friendly software design

It cannot be denied that the health domain is extremely sensitive, and every aspect that interferes with traditional processes is potentiated in terms of impact. Thus, we started this project assessing the influence that a technological environment would have in the patient’s behaviour.

KMS can and should be used in order to optimise certain procedures, but the type of organisation they are introduced in must be kept in mind. Dimensions and items for a model of knowledge management were presented in Table 1.

The purpose of this paper involved the development of a platform that would not interfere with patient’s answers when used, and that could be used and applied by health professionals. This software should run through a browser working in the health unit’s intranet, or even in the internet.

The main requirement in the creation of this software was building an interface as close to a traditional paper form as possible. Using keywords like usability, accessibility and confidentiality, the intention was to build a simple interface with an intuitive use, where the correction to an answer could be done in a clear, objective way, where the patient could clearly understand the confidentiality of his answers, and accessible to all types of patients. Blind, illiterate and physically challenged individuals are recurrent amongst the frequent oncology service patients of the Portuguese Institute of Oncology (IPO) in Oporto. Sound or touch screens are presently the two used interface solutions, but we are still investigating the use of other communication devices.

Next, we show two figures. Figure 1 represents a view of the QoL screen and Figure 2 shows a view of the patient’s screen when he answers the questionnaire.

Figure 1  View of the QoL screen (see online version for colours)
5 Methodology and results

In order to assess the impact created by the application in the given answers, we randomly selected patients from the otorhinolaryngology service in Oporto’s IPO. We selected 15 days from May, June and July, and all patients attending consultations on those days were invited to participate in this study. All of them accepted the invitation. We obtained a sample of 54 individuals. These patients answered the same questionnaire twice, one in paper form – the traditional model – and the other on the computer using the software developed for that purpose, with 40 minutes temporal gap. Half of the patients answered first on the paper form and the other half answered first on the computer platform, the minimum time between answers was 40 minutes. In both cases, the answer time was measured and the patient’s preference between the paper and the computer was registered. Information regarding patient’s affinity with computer use was also registered.

In order to understand if the computer-based environment influenced or not the answers, we analysed the obtained values for each given answer in both of the assessment moments using a collection of statistical models and tests. Answers obtained in paper format and through the computer-based platform were matched. To understand if the computer-based platform did not influence the patients’ answers, we hypothesised that distributions for each variable in study were identical. We first tested the entire set of answers and then two subsets, which divided patients that answered firstly on paper and patients that answered firstly on the computer.

In the validation process, two questionnaires were used, both from European Organisation for Research and Treatment of Cancer (EORTC): QLQ-C30 and QLQ-H&N35. The first one is a global questionnaire developed for all type oncologic patients. It has 30 questions grouped in five domains (physical, social, emotional, functional and cognitive). The second is a specific questionnaire for head and neck oncology patients, with 35 questions.

The two statistical hypotheses for a bilateral test in each situation were written:
Hypothesis $H_0$: $F(X_o) = F(X_i)$; Hypothesis $H_1$: $F(X_o) \neq F(X_i)$

We used the Wilcoxon test, the most appropriate when the dependent variable is measured in an ordinal scale (Maroco, 2007). In both of the questionnaires (QLQ-C30 and QLQ-H&N35) adopted to evaluate the QoL, the test results did not allow to conclude if there were significant differences between distributions, for the two samples and the three mentioned situations.

A high level of significance was always attained, independently of the global or the partial analysis of the sample, divided between those who firstly answered on paper and those who firstly answered on the computer, so the hypothesis of a significant difference between answers not existing was accepted. We can, thus, state that the software use does not bias patient’s answers.

The following graphics (Figures 3 and 4) show, for each question, the percentage of equal and different answers given by patients answering on the computer in a comparison with answers given on paper.

**Figure 3** QLQ-C30 answers comparison
We, thus, concluded that the answers given by patients on paper and on the computer-based platform are generally the same. Answers q1, q2, q22 of QLQ-C30 and answer h41 of QLQ-H&N35 show the higher number of different answers, a little over 40%, in the case of h41, fewer than 40% on the other cases.

It is worth noting that the specific questionnaire (QLQ-H&N35) reveals a higher proportion of equal answers. Ideally, the answers should always be the same, but previous experiments (performed on paper) show that answers given by patients in two separate moments are sometimes different, and the percentage for this difference is close to the one we observed between the answers on paper and the answers on the computer. This confirms the results observed in the mentioned test, leading us to conclude that the different results are caused by other factors.

We wanted to know the opinion of patients about their preferences regarding the means used to answer the questionnaire. Patients prefer the platform or the paper? To this end, we discriminate patients into four levels of computer usage: None, little, some, substantial. The results are shown in Figure 5.
The results show that only patients whose level of computer use is none prefer to use paper as the resource for answering the questionnaire. It is also clear that there is a direct relationship between the level of patient computer usage and preference by the platform.

6 Data analysis

After the information registration stage, concerning the patient’s QoL, it is important to forward this information in a clear and objective way to the physician, to enable an improved decision making. The following stage was the clinical variables identification and development of the output information obtained from physicians contributions.

Measures verified in clinical analysis differentiate patients from each other, but we understand that QoL measuring should also be considered in patient standardisation.

We used the Rasch model (Christensen, 2004) to analyse the patient’s answers. An important feature of Rasch model is the sufficiency of the raw score making consistent estimation of item parameters without reference to the distribution of the latent variable in the population possible. This feature allows analysing each answer from each patient individually without concern with the others’ answers or the population distribution.

Figure 6 shows a patient’s answers: signalled in yellow are the answers that are below the expected for this type of patient, and signalled in blue are the ones above the expected. In the right column, the most critical answers are highlighted in order to make it easier and quick for the physician to understand.

The advantage of using this platform is that it provides a quick analysis by the physician about the patient’s clinical problems. In fact, the physician takes note of patient problems before observing the patient. This information facilitates and improves the conduction of the appointment. Without using the platform, is not possible to identify some signs and symptoms.
Clinical decision support system

Why is this system a clinical decision support system?

In addition to information about QoL, the platform can register the patient’s clinical information and socio-demographic characteristics allowing classifying and grouping patients according to these characteristics.

The collected data can help the physician in two levels:

- identify the problems that the patient has at the moment
- assists the physician in decision-making by providing a forecast of future QoL of the patient according to the treatments prescribed today.

It is important that the patient and the doctor know the effect that a treatment will be within three, four or five years in your QoL.

The decision about choosing a treatment protocol should include the patient’s QoL not necessarily during the treatment but especially during the years following this.
The objective measurement of QoL of the patient allows, in this context, and considers it as a clinical data contributing to the characterisation of the patient.

8 Conclusions

In this paper, we defined the concept of QoL, in different contexts and situations, which reaches almost every sector of society. The main focus, however, was on the health context.

Some studies have suggested that the implementation of a patient HRQoL assessment in Portugal is challenged and questioned for several factors involving health institutions, health professionals and patients (Rodrigues, 1998). The reasons include: a lack of familiarity with relevant studies in this area; the absence of sensitivity; lack of time; reluctance in accepting that the patient’s perceptions regarding their own outcomes are as important as the physicians (Caçador et al., 2001); difficulty in quantifying subjective parameters; difficulty in converting tacit knowledge in explicit knowledge; inexistence of friendly computer-based applications; inexistence of health care service infrastructures that enable a routine HRQoL assessment.

This platform gives the physician an opportunity to use the patient’s QoL measurement in real time as clinical decision support elements.

The knowledge about patient QoL constitutes another factor that may, in certain circumstances, contribute to a better decision. The systematic patient QoL data collection allows the standardisation of this information and to infer therapeutic strategies for a specific patient. Moreover, therapeutic alternatives can help the physician by giving him important data from which he can infer the patient’s future QoL.

We proved the validity of the developed platform in the acquisition of data required for the QoL assessment, and in allowing a routine QoL assessment to become a part of the appointment.

An evolution of the platform for the collection of clinical information, in order to typify patients and therapies according to a specific patient’s QoL and a class of patients, has already been made. The need to develop this platform underlines the importance of KMS as decision making aids.

References


