More information, more choice: an Italian database for oncology patients

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Background: In recent years there has been a proliferation of cancer information available for patients in the Italian language. However, quantity without validation and organization is by no means synonymous with providing good information and a good service. Furthermore, the lack of coordination and cooperation between the various information-providing initiatives results in uncontrolled waste.

Materials and methods: To impose order on the vast ocean of cancer information in Italian, and to provide patients with a reliable and comprehensive tool, the Azalea Project was developed whereby a database of information for patients was created. Paper-based and electronic information is validated and stored so that patients can search and retrieve it. Validation is by means of a grid drawn up by the project team with reference to international standards.

Results: The nucleus of the database constructed by the Centro di Riferimento Oncologico (Oncology Referral Centre), Aviano, was extended using the wide experience of the Italian Cancer Institutes within the Italian Alliance Against Cancer. The website is at http://www.azaleaweb.it

Conclusions: Meetings and courses specially designed for the project enabled evaluation grids to be created and permitted a fruitful interchange of skills and experience from a variety of professional information providers united in the common aim of providing patients with a service that meets their needs and puts them in control at a difficult time in their lives.

Key words: databases, Internet, neoplasms, patient education, popular works

Background

Communication from doctor to patient and vice versa is the key to a successful consultation. Many patients still feel that they are entering ‘alien territory’ when they go to see their doctor. In many cases they are scared, they don’t understand what the doctor is saying, and they are not able to take everything in that they are told. Just as doctors may have trouble understanding a patient’s explanation of symptoms, so patients may have trouble understanding a doctor’s explanation of the diagnosis [1].

This statement, from Mike Stone, Director of the UK Patients Association, published in the British Medical Journal, clearly highlights a crucial aspect of the doctor–patient relationship, namely the difficulty in reciprocal understanding in a situation where two people who are speaking about the same subject have widely differing levels of subject knowledge. The doctor knows the subject in depth, whereas the patient may have no knowledge whatsoever. At one time this gulf in understanding was generally and passively accepted; nowadays however, the vast majority of patients want to participate in the decisions that affect their health, or at the very least have an understanding of the reasons behind certain treatment options and decisions.

It has been shown that doctors only proffer minimal information during a patient consultation, despite the fact that patients from all socioeconomic backgrounds are showing an ever-increasing desire to seek medical information, particularly via the Internet. The doctor–patient relationship is likely to undergo a sea change as a result of these attitudes and behaviours [2]. Patients are often dissatisfied with the amount and quality of information they receive. Additionally, many patients are unable to participate to the extent that they wish in decisions about their own care, and doctors frequently fail to recognize or appreciate the role that their patients would prefer to assume in decision-making [3]. The need for active participation is keenly felt in the field of cancer, where awareness and knowledge of one’s disease can in many cases alleviate, at least to some extent, the fears and anxieties experienced in the face of ‘the unknown’ [4–12].

Based on a meta-analysis of 24 published surveys, it emerged that approximately 39% of people with cancer use the Internet, and approximately 2.3 million people with cancer worldwide are
Thus patients are enabled to obtain detailed, up-to-date and specific information about their illness. Among these patients, 53.7% reported that the information they received from their physicians and other healthcare providers was insufficient. Most patients (71%) searched for information about their illness, with the Internet being the most popular choice. Searching for information did not reflect a lack of trust in their physician. When patients tried to discuss the information with their physician, most (88.3%) found that he or she was willing to discuss information found on the Internet, and 67.3% found that their physician spent a lot of time (16.4%) or a moderate amount of time (50.9%) discussing this information with them [14].

In Italy, recent studies attest to the desire for information on the part of the patient, above all regarding diagnosis, prognosis and treatment [15–17]. A study carried out in 1998 at the Centro di Riferimento Oncologico (CRO), Aviano, revealed that such a desire does not arise from a poor relationship with the doctor, but from a need to acquire personally knowledge of the disease and awareness and understanding of the treatment possibilities via neutral and unbiased sources [18]. Similar Italian studies, undertaken several years earlier, demonstrated that 90% of patients obtain their health information from non-medical sources [19, 20]. Currently, some 5 million Italians search for medical or healthcare information on the Internet [21].

When faced with a health problem, the most important thing for 83.6% of Italians is to ‘understand what is happening’. The doctor remains the individual in whom Italians place the greatest trust and from whom they derive their information. However, the data highlight a growing faith in the Internet (60.2% evaluate its use positively), and younger users affirm that gaining medical information from the Internet ‘develops scientific culture’ and view its use by doctors favourably as it will ‘enable them to update their knowledge in real time’ [22].

As a consequence of the ever-increasing use of the Internet in Italy, we have witnessed a veritable profusion of information in the Italian language targeted towards patients to meet their equally ever-increasing demands. A recent survey of Italian websites showed that 80% of them did not state when their last update was made and that only 7.4% of health-related sites bore any certification of quality [21]. With regard to the recent increase in requests for information by patients, it cannot be emphasized enough that, in the field of oncology, quantity without validation, management, organization and specific knowledge will lead to a poor service for patients. This has provided added impetus for creating an Italian database of literature for patients and the public, where information in Italian aimed specifically at cancer patients is collected, organized and validated. Thus patients are enabled to obtain detailed, up-to-date and straightforward answers to their questions [23].

In 1997–1998 the CRO, Aviano, started to develop the nucleus of a database comprising ~700 records related to information about cancer and ~350 records related to the authors (mostly patient associations and non-profit organizations). In 2003 the project was extended nationwide when the Alleanza Contro il Cancro (ACC, Alliance Against Cancer), a body set up by the Ministry of Health, recognized its national importance. Therefore it was broadened to include collaboration of the seven oncology Scientific Institutes for Research, Hospitalization and Health Care (IRCCS), thus becoming a multicenter project financed by the Ministry through the ACC. The name Azalea was chosen because azalea plants are distributed in Italian piazzas by the Italian Association for Cancer Research (AIRC) when collecting funds for research.

### Materials and methods

The study carried out in Aviano in 1998 revealed that there was a clear need for satisfying patients’ desire for improved knowledge by providing scientifically accurate, up-to-date and easily understood answers to their questions. Therefore the objective of Azalea is to offer the non-specialist consumer ready access to validated information and enable users to gain as much knowledge as they need about a particular cancer condition, confident in the knowledge that the service offered is up to date.

Azalea also aims to enrich the work of those providing materials aimed at cancer patients and the general public, to stimulate the production of other materials regarding research discoveries and to increase the visibility of voluntary and non-voluntary medical and scientific bodies. To do this it collects, evaluates and catalogues material in accordance with international bibliographic standards of description and indexing of documents. The information sources (originally in Italian or translated from English) include books, journals, book chapters, articles, leaflets, compact discs, cassettes and websites. Although some of this material is simply referenced and described, some of it is downloadable in its entirety. At the time of writing, Azalea comprises 1620 records related to all kinds of materials (580 of them are full text, 49 documents have undergone the quality control process and a further 87 are still in the evaluation phase), 212 evaluated websites, and records for 1381 associations and organizations.


The work of Azalea involves librarians, information scientists, informatics experts, psychologists, doctors and nurses in collaboration with the voluntary associations and medical and scientific organizations who have made their materials available.

In this initial phase of the project one of the primary objectives, arising from the work of Eysenbach and colleagues [28–30], is the constitution of a Materials Evaluation Committee whose job is to assess every document input into the database on the basis of evaluation grids drawn up from a study of similar grids described in the literature [31–34]. The documents to be evaluated are submitted to a mixed group consisting of psychologists, but also including librarians and experts in the humanities, who will evaluate the communicative style, and a mixed group of doctors of various specialties, biologists, pharmacologists etc. who will analyse the content. Three grids are used for the evaluation, one for each of the three aspects, drawn up on the basis of the literature on information resource evaluation. Each grid consists of several criteria to use for document evaluation.

1. Technical–formal aspects (to be completed by the librarian): transparency; appropriateness; authority; currency and date; interactivity; accessibility and usability; standards and conduct criteria.
2. Communicative style (to be completed by the psychology–humanities staff): comprehensibility of information; relevance of information; emotional impact of the information.

3. Content (to be completed by the psychology–oncology staff): validity; precautions; usefulness.

The evaluator (or group of evaluators) is requested to assign a score (the model proposed involves an evaluation in accordance with the Discern model with a scale of 1–5 as in the Likert scale) for each criterion and to write a brief summary (no more than three lines) highlighting the strong and any weak points of the document. The evaluator is also required to indicate whether the document is appropriate for what we define as ‘first-level’ information, i.e. information which is aimed at cancer patients, their relatives and the general public who have no pre-existing knowledge of the subject matter, or whether it provides ‘second-level’ information, i.e. information aimed at a more expert public, such as those cancer patients and relatives who have become well acquainted with the material. The final summary is written by the professional librarian of Azalea team.

It is important to point out that there is no intention of making value judgements or censoring the documents in question. Rather, it is important to convey the idea to patients and the general public that ‘evaluation is possible’, and that tools based on criteria which are as objective as possible are available to do this.

The Azalea database is designed so as to facilitate information retrieval by those with little or no expertise. In fact, it is possible to conduct a search by inputting commonly used terms. However, it is more effective to search using keywords which have already been assigned to each record. Such keywords provide an in-depth description of the subjects dealt with in the database. Those who want to search the database are presented with a choice of descriptive terms from a readily accessible list so they can pinpoint their topic of interest.

The keywords, which are assigned by professional cataloguers from the project team, are drawn from the Italian version of the Medical Subject Headings (MeSH), the thesaurus created to index the Medline database and translated a few years ago by the Documentation Service of the Istituto Superiore di Sanità (Superior Institute of Health), Rome. The MeSH thesaurus is used not only in biomedical databases all over the world, but also by quality health portals such as OMNI/BIOME, by European projects such as MEDCIRCLE and by databases that reference sites on the basis of quality, such as HONselect from the Health On the Net Foundation who have developed the HONcode, a code which guarantees the quality of selected biomedical sites [29,35,36].

Results

Since July 2003 the database has been accessible via the ACC portal e-oncology (http://www.e-oncology.it): the first experimental version of Azalea on the web. However, the software is being completely revised by a team of technicians from the CRO, Aviano, and the Consortium of Bioengineering and Medical Informatics of the University of Pavia (CBIM). One of the main features is that the input of new data into the archive of this new software takes place in a shared mode over the Internet by authorized expert partners of the project team. Therefore information in process will be accessible to users through Azalea in real time before the citations are validated by the multicentric validation team. In addition, two levels of authority are maintained to ensure that the records input by different libraries adhere to the cataloguing standards.

The first version of this software was launched on April 5, 2004 at the Cernobbio Heath Forum, an important Italian exhibition. On April 28, Azalea Day, an Azalea team meeting was held to teach partners how to work together using the new software. The system (http://www.azaleaweb.it) (Fig. 1) enables easy access to reviewed documents. If they are unavailable in full text, the user is told how they can be obtained, either directly from the document producers (authors or associations) or from the libraries participating in the project which have set up purpose-built document supply services. In this way those who produce cancer information for patients, such as associations in the field of oncology, medical and scientific organizations and hospitals, can become better known to the public, and easily contactable, irrespective of whether or not they have websites, and regardless of their physical location. A ‘database of associations’ is conveniently integrated into the principal database.

The statistical reports detailing the initial number of visits to the database between May 2004 and May 2005 show a constant increase in the number of visitors (Fig. 2A). Figure 2B shows a progressive increase in visits at the weekend, which one would hypothesize as being predominantly by patients and families rather than by specialists in the field.

Figure 3 shows the number of searches conducted on the Azalea database over a period of 1 year. The number of searches that concluded with the display of information or the request for a document from one of the Azalea libraries is highlighted (61% of total searches). A progressive increase in searches and viewed documents is observed from the time that the database was first made available to the public (May 2004). Data for March 2005 were unavailable because of technical problems with the server.

Only a partial analysis has been conducted so far. An investigation over a prolonged period might reveal further characteristics of Azalea’s website access and thereby enable the product to be tailored even more closely to user needs.

No detailed information is currently available concerning the types of users who access Azalea. A questionnaire was recently made available, which can be completed online, and this will yield information on requester characteristics, topics searched for, and degree of user satisfaction. Furthermore, the questionnaire will provide information which will prove useful in developing the database, enhancing and tailoring its content and presentation, and investigating new ways of searching for cancer information.

Conclusions

It is well known that the amount of information with which we are bombarded never ceases, and the all-pervasiveness of the Internet adds to the confusion inherent in the information explosion. The general public and patients need information of quality so that they can ‘get better at asking questions and understanding the answers’. Health care workers require that the material on offer to the public is intelligently and critically evaluated and that the public is encouraged to use it well. When everything is taken into consideration, it is a matter of ensuring that informed consent is well and truly ‘informed’. If the information with which the patient and doctor work is of consistently high quality,
the benefits to the doctor–patient relationship, and indeed to medicine in general, are obvious.

The organization and the visibility or retrievability of the resources enables each centre to rationalize its services, avoiding duplication or omissions in the holdings of materials for the ‘non-scientific community’ and a uniform classification and indexing of such material. Collaboration between the various partners is fundamental to ensure updating, improvement and
development of Project Azalea both from a qualitative and a quantitative point of view.

After the first year of use, an analysis of the continuously increasing visits to the site, show that the public viewed almost 16,000 documents in a single month (May 2005). Some documents were downloaded directly from the server in pdf format, some were requested as print documents from the holding library and others were viewed by linking directly to the producer’s site (association or research body).

Italy is on the threshold of being able to make an original contribution to the sector of quality information for patients. Azalea hopes to fill the information gap that exists between Italy

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**Figure 2.** (A) Number of visits to the Azalea website between May 2004 and May 2005. (B) Number of weekend visits to the Azalea website between May 2004 and May 2005.

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**Figure 3.** Number of searches and documents viewed on the Azalea website between May 2004 and May 2005.
and other European countries and the USA with the creation and continuous update of the first multicentric digital library in the Italian language.

References