

Giving Voice to Patients: the Editorial Support of a Library for Patients

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Introduction

In the Google era, librarians must not be afraid of contamination. In the information field, there are many areas where other specialists have greater expertise than librarians but in many others no one has the knowledge and interest to address the relevant issues.

As the Medical Library Association shows in its fascinating presentation “Myths and Truths about Library Services¹”, it is a myth that “the quality of patient care is unaffected by library services”. As Weightman states the truth is that “research has shown that libraries improve patient care” (1).

Such has been our experience offering a Patients’ Library (PL), developed as a section of the Scientific Library in activity since 1998 within the Centro di Riferimento Oncologico (CRO): the National Cancer Institute of Aviano, Italy. The CRO PL ²deals with many patients - about 500 physical patients a year requesting additional information about their illness (2).

Within our Institute, the library is divided into two sections: an Oncology Information Point and a Leisure Reading section. In the recreational areas there are a number of available books for leisure mainly held for patients passing through. These texts are made available by librarians and offered in addition to other leisurely activities organized by the hospital’s Volunteers. In the same areas copybooks such as “large, memorandum-style compendia” are also available.

Aim

Giving voice to the patients was our goal.

Methods, results e discussion

During the last five years, patients, their relatives and friends, and other visitors have filled these copybooks (memo-style) with their thoughts, poems, drawings and emotions. Relatives of a deceased patient have also address us asking if it would be possible to read the writings of their beloved one. As librarians, this and other hints suggested us the need to support the patients’ desire for expression, so to guide them in their need for both writing as a means to better cope with their illness and reading about similar experiences faced by others. So we edited and published a first book “Caro G.A.S”, 2002, whose authors were all the people who had left some of their thoughts in the first copybook (Fig. 1).

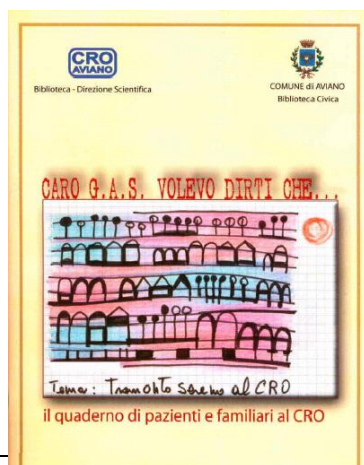


Fig. 1

“Dear G.A.S. (“Group of Patients’ Social Entertainers”) I wished to tell you at...the copybook of patients and their relatives at the CRO”

¹ www.mlanet.org/resources/vital/index.html

² http://www.cro.sanita.fvg.it/biblioteca/bibpaz/txt_info_bibpaz.htm

A slightly revised second edition was published in 2004 and a new, completely different book, “Passaggio al CRO” (Fig. 2) was launched in 2006³.

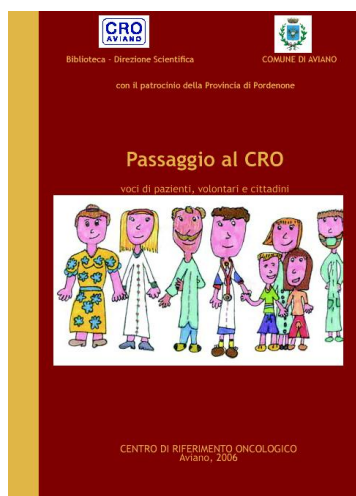


Fig. 2

“Passage to CRO: voices of patients, volunteers and citizens”

Conclusions

The writings in these publications are an example of the means by which a part of one’s life, even in the context of illness, can be brought to the readers - introducing them into one’s own world -, thus actively sharing the experience⁴(3). All these publications are available free of charge and have been presented in special events, so to become an occasion to establish a deeper relationship between the healthy and the ill, as well as to discuss issues relating to coping with cancer.

A survey among high school students concerning the impact of these presentations will be presented in the course of the intervention. Besides, a new edition is in course of preparation, a result of the special collaboration among the CRO Library, the CRO Youth Division, the local Public Library and several local high schools.

Finally, we can state that librarian skills are an important way to give patients a stronger voice. In our experience, librarians showed by far the strongest interest and motivation in collecting the patients’ writings in respect of their intellectual property, communicating with them about copyright, privacy laws and other relevant topics, editing and publishing the publications and using them as a means to really empower the patients and their relatives.

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Reference

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³ http://www.cro.sanita.fvg.it/biblioteca/bibpaz/txt_publicazioni.htm

⁴ <http://www.dipex.org/Home.aspx>

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