

# Teaching and Learning in Action

## Abstract

In this article, guest writer Ivana Truccolo presents an overview of her work at the Scientific and Patient Library of a Cancer Comprehensive Centre in Italy coordinating the patient education process. She discusses the historical evolution of the concept of patient education and how this has run alongside the role of the health librarian in the provision of consumer health information. Details are provided about various patient education programmes in place at the Centre. In particular, various activities are discussed including patient education classes, the development of patient education handouts and a narrative medicine programme which includes a literary competition. The article concludes with a specific outline of the role the health librarian can play in the provision of consumer health information and patient education.

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*Keywords:* consumer health information; education and training; health information needs; information literacy; patient education; patient information; patient participation; patient support groups

## Providing patient information and education in practice: the role of the health librarian

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## Introduction

About 20 years ago, the Bulletin of the Medical Library Association (MLA) published a visionary

paper written by the Patient Health Information Section (CAPHIS) of the MLA about the role of the librarian in the provision of consumer health information and patient education.<sup>1</sup> This position paper was remarkable because of the identification of an overlapping in practice between the two concepts of consumer health information (CHI) and patient education (PE) and of a potential role for health librarians in these two areas. CAPHIS/MLA defines PE as ‘a planned activity, initiated by a health professional, whose aim is to impart knowledge, attitudes and skills, with the specific goal of changing behaviour, increasing compliance with therapy and, thereby, improving health’, whereas CHI is defined as ‘information on health and medical topics provided in response to requests from the general public, including patients and their families. In addition to information on the symptoms, diagnosis, and treatment disease, CHI encompasses information on health promotion, preventive medicine, the determinants of health and accessing the health care system . . . CHI and PE overlap in practice, since patient behaviour may change as a result of receiving health information materials. PE and CHI differ in terms of the setting in which the process occurs, rather than in terms of the subject’.<sup>1</sup> Stating that health librarians had a potential role in the delivery of patient education was a bold and challenging statement to make because at the time, this activity was very much viewed as a domain owned only by health professionals.

In this article, a different concept of patient education is proposed. Working as head librarian in the Scientific & Patient Library of a Cancer Comprehensive Center in Italy (the Centro di Riferimento Oncologico CRO in Aviano, north-eastern Italy) has offered me the opportunity to experience in practice the role that a librarian can play in the delivery of both CHI and PE. The following sections offer some practical examples of how the health librarian can have a role in this field.

### The evolution of the patient education concept

It is important to identify the practical evolution of the concept of PE because it runs alongside the evolution of the role of the health librarian,<sup>2</sup> particularly of the consumer health librarian, and with their potential role in the PE field. The MeSH definition given by Medline for 'Patient Education as Topic' is 'the teaching or training of patients concerning their own health needs'. The first article indexed in PubMed/Medline with this term dates back to 1946<sup>3</sup> and considered educational material for patients on tuberculosis. Research activities in patient education are also evident in other older publications.<sup>4,5</sup> Within these articles, the education of the patients reflected the paternalistic approach in medicine that was common at that time, that is 'top down' education in which the health care professionals had the knowledge, while the patients were expected to learn and be trained to increase their compliance.

Some years ago in 1989, the National Cancer Institute (NCI) USA launched the idea of bringing together the professionals involved in the PE process from the NCI-designated Comprehensive Cancer Centers, to share the tools and approaches they used to provide cancer education to patients and their families. From this, the Cancer Patient Education Network (CPEN) USA was established.<sup>6</sup> The aim of this venture was to 'achieve best practices in education that enabled cancer patients, their families and caregivers, to more easily navigate the health care system, better understand their diagnosis, tests and treatments and deal with the uncertainty of living with cancer'. Furthermore, the vision also included the incorporation of 'formal education interventions as integral components of cancer patient care'.<sup>6</sup> The CPEN set out some standards of practice<sup>7</sup> addressing 4 key points for an effective patient education plan in the health care organisations:

- The presence of an institutional commitment to the PE activities
- A method of organisation of the different PE activities
- Active involvement of patients/caregivers
- Kind and role of the different HCW (Health Care Workers) in the PE activities

The focus of this initiative was to create a shift from an individual, optional, spontaneous, 'naïf' approach to the provision of PE towards a more organised one. Since then, there have been a number of occurrences that have affected this initiative.

The digital, Internet era with its global access to information, has profoundly affected methods of education delivery. In the context of health care, we are now in the 'patient revolution' era<sup>8</sup> alongside lifelong learning and cancer survivorship.<sup>9</sup> People are now considered more responsible for their health and the physician–patient relationship is moving towards partnership.<sup>8</sup> However, the power of information can be meaningless and illusory if patients do not have the instruments to understand, select and use trustworthy information for making appropriate decisions about their own health needs,<sup>10,11</sup> or in other words, a good level of health literacy. In 2013, the Patient Information Forum (PIF), the UK's largest membership organisation for people working in health information published a key document addressing the importance of producing and providing good quality health information.<sup>12</sup> And of the asymmetry of power and knowledge? A year prior to this, the Lancet published an Editorial entitled 'Patient empowerment. Who empowers whom?'.<sup>13</sup> While reporting on key topics of the recent first European Conference on Patient Empowerment, the Editor quoted a sentence by Robert Johnstone of the International Alliance of Patients Organization who stated, 'doctors should get down from their pedestals, but patients must get up from their knees ... empowerment is not about trying to wrest power from the doctors. Instead, it is essentially about helping people lead more proactive and fulfilling lives'.<sup>13</sup>

Over the past three to four decades, the concept of patient education has changed considerably due to the inclusion of new and old-revised concepts such as empowerment, involvement, engagement, self-management, preferences, advocacy, partnership, health promotion, health literacy, information and communication of/and/with/for the patients. This change of paradigm is towards a more proactive and bidirectional approach. It is not only doctors, nurses, technicians and health

care workers teaching and training patients about their own specific health needs, but increasingly patients are playing an active role in that teaching and training to a different modality of physician–patient relationship. This is because ‘patients, far more than clinicians, understand the impact of disease and treatment’<sup>8</sup> and can play an integral role in the reorganisation of the health services. Furthermore, other professionals along with the patients are involved in the patient education process, and among them, consumer health librarians because of the unique skills set they can bring to the table in terms of their ability to identify, select, organise and disseminate health care information.<sup>1</sup> Indeed, the involvement of the health librarian can be strategic in this shift.

### **The Patient Education Programme and Team at the CRO Aviano**

In 2010, at the Centro di Riferimento Oncologico of Aviano (CRO), one of the Italian Cancer Comprehensive Centers in Northeastern Italy, the librarian was appointed as the technical coordinator of an institutional Patient Education & Empowerment Program. This occurred as an outcome of the qualified activities of the CRO Patient Library since 1998. The CRO Patient Library is a pilot project in Italy in the cancer patient information field.<sup>14</sup> It was established as a section of the CRO Scientific Library (1984) for supporting the information needs of patients, their families and citizens. After some years, the library was renamed as the CRO Scientific & Patients Library, which essentially meant it was a unit of the Scientific Directorate with an enlarged mission and vision. The Patient Library became pivotal in the PE process within the organisation, that is of the patients’ involvement in the planning, doing, checking and acting upon of all the patient information and communication activities and of some organisational and research topics as well.<sup>15,16</sup>

In the following sections, we present some details and reflections about this experience. In particular, we focus on the patient education process, the skills that a health librarian can use to play an effective role in this field, and how this can affect patient care.

### **Overview of activities**

At the CRO Aviano, the Scientific Directorate started up a Patient Education Program in late 2009 based on a preliminary collaboration with the Patient Education Team of the Princess Margaret Care Centre, Toronto, Canada. In 2010, the Scientific Director established a Patient Education & Empowerment Group (PEEG) charging the health librarian with the role of technical coordinator of the team and programme. The PEEG is one of the key points of the application of the CPEN standards highlighted earlier. It is a multi-professional, trans-disciplinary, non-hierarchical team, including doctors, nurses, health technicians, biologists, administration positions, librarians and, as essential components, patient representatives and volunteers. The members were suggested by the different CRO Department Heads and/or chosen by the Cancer Patient and Volunteers Associations collaborating with our institute. The PEEG is an open, enlarged team but based on a core group which operates as an open steering committee. The PEEG activities are carried out by ad hoc subgroups. Since the beginning, short, medium and long-term programmes have been planned, executed and checked together with the patient representatives. The PE programme is part of the CRO Annual Plan. The PE programme is defined by different activities relating to three specific areas: research, education and information and communication, and these are centred around the Scientific and Patient Library. Other services are involved in these activities include the Continuing Education Office, the Pharmacy and all the health facilities. Some of the main activities organised at our Institute are highlighted below.

### **Classes**

We run hour-long meetings named ‘classes’ where doctors, health care workers, librarians, expert patients and volunteers, as teachers, speak to other patients and their relatives about relevant health topics during the daily activity hours in the hospital setting. The topics are chosen by listening

to the health care workers and the patients' information needs and modified according to their suggestions (short customer satisfaction questionnaires were administered after each meeting). Over recent years, we have been able to move to data collection for the purposes of research into this work. This started with 6 meetings in 2012, involving 13 health care workers, expert patients and other professionals involved as 'teachers' and around 400 patients and relative participants. These numbers have now grown with 46 teachers and 556 patients/relatives being involved in 2014, covering approximately 15 different topics. In 2015, the number of teachers increased to 50 with the number of patients/relatives staying around the same as the previous year.

The librarian is the coordinator of this educational activity which is ongoing. This role aims specifically to improve the dialogue between patients and experts, giving voice to patient requests, helping experts to listen carefully and use plain language, teaching about the tools for assessing the quality of health information on the Internet and taking into account user feedback for planning future sessions.

Based on the experiences of running these classes, the health librarian has subsequently co-authored and edited some specific recommendations around how to write for and with patients about health topics. The production of these recommendations was based on guidance taken from elsewhere in the literature addressing how to write for and with patients about health topics.<sup>17</sup>

### Patient education handouts

Patient education handouts about relevant topics are written by health care workers but are accurately revised by a subgroup of the PEEG comprising psychologists, librarians, drug experts, patients and laymen. The role of the group is to review and evaluate the educational materials before they go to print. In particular, aspects such as the coherency, clarity and plain language communication style of the documents produced are considered by the review group. Specific review criteria are used in the review process

including the ETHIC© checklist,<sup>18</sup> an evaluation tool for health information produced for consumers.

The librarian has the scope within this role to develop a real collaboration with patients and citizens in producing the patient education handouts. Once produced, all materials are indexed by the librarians on the online database CIGNOweb,<sup>19</sup> a national project managed by the CRO library which is an Italian digital repository of trustworthy health resources for cancer patients. This resource fills a gap which had previously existed in this area.

### Narrative Medicine Programme

The tradition of the CRO Patient Library of giving voice to the patient stories led to the adopting of a Narrative Medicine (NM) Programme. This is part of our wider PE institutional programme and is an approach to medicine that recognises the value of patient narratives in clinical practice, research and education.<sup>20,21</sup> One of the activities coordinated by the health librarian is an annual 'Artistic-Literary Competition' which is open to patients, health care workers and caregivers dealing with cancer. The originality, creativity and use of metaphor are encouraged. More than 170 participants have contributed to the past four literary competitions with stories, brief novels and life experiences about a specific topic. The programme has been found to be very empowering for both patients, health care workers, caregivers, students and librarians.<sup>22</sup> As well as organising the event, the health librarians play an important and active role in running it including acting as story reader or as general arts & literature 'expert' through close collaboration with public and/or academic librarians. The librarian also manages the panel that does the analysis and selection of works submitted to the competition and compiles and edits the anthology books (four so far) containing selected works from it. Indeed, as Curran states, 'the medical humanities present great possibilities for librarians to find even more ways to make themselves indispensable to their users'.<sup>23</sup>

This article has outlined only a sample of the activities related to current PE and CHI; however,

the health consumer librarian is involved in many other related activities. At our Institute, the librarian is also involved as project manager of a 3-year-long multi-centre collaborative project (2013-2015) granted by the National Health Authority in Italy entitled 'Extending Comprehensive Cancer Centers expertise in patient education: the power of partnership with patient representatives'.<sup>24</sup>

## Conclusions

In summary, the role the health librarian plays in practice in this intensive and challenging work is as follows:

- To coordinate the PE team and the different groups and activities fostering real patient participation.
- To organise the production of patient education handouts according to a real co-productive approach.
- To support patients in strengthening their priorities and ease the communication process.
- To help doctors in 'learning' from their patients.
- To involve other physicians and other professionals in the PE process.
- To check the different activities and use the feedback to improve them.
- To make an expert evaluation of Internet-based health information and help patients to become more cautious on certain controversial and deceptive issues.
- To make bibliographic searches about the different PE topics, select the appropriate evidence-based resources.
- To produce and update a full text database of information resources for patients.
- To promote, support and collaborate in research about PE issues.
- To write scientific communications, papers, practical recommendations and to diffuse them in the scientific and non-scientific community.
- To create a network with other organisations for promoting a bidirectional approach in the PE field.

This article has demonstrated how the healthcare librarian can provide added value through

coordinating the whole patient education process. Taking advantage of a relatively low position in the organisation but, at the same time, authoritative by being affiliated to the Scientific Directorate, has provided a valuable contribution to the change of an organisational culture from one of disease-based medicines towards one of patient-centred/citizen-centred care. Through these particular activities, the librarian can indeed become a patient education catalyst.

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