

**1. Proposers:**

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**2. Statement of the Topic:**

Cancer Patients' Perceptions and Expectations of Health and Medical Information Services in Japan's Public Libraries

**3. Significance and Relevance of the Topic:**

This is a descriptive study of cancer patients' use of public libraries, embedded within their information-seeking behaviour and the framework of the conference. Based on the study, we have identified methods of improving public library health information services, which is significant in terms of informing practices.

**4. Contents**

**Background:** In the last decade, with the enforcement of the Cancer Control Act on April 1, 2007, national and public entities have been required to take necessary measures to collect and offer information on cancer treatment and extend advice and aid to victims. Accordingly, shared decision-making between medical professionals and patients must be considered as a recommended model for increasing patient autonomy. Public libraries have become one of the local avenues for providing health and medical information to cancer patients. A survey of all 1,355 local governments with public libraries, conducted in 2013/14 by the Health Information Committee of the Japan Library Association (2014), indicated that approximately 42% of the 916 respondents reported increased demands on materials and references regarding health-related topics (treatments, hospitals, medicine, hygiene and so on) in public libraries. In response to these demands, approximately 24% of these libraries have established a section for such materials, including books, journals and pamphlets, that is independent of the general collection.

**Method:** Interviews were conducted with 18 members of the Japanese Citizen Panel, consisting of seventeen cancer patients and one family member, of the Center for Cancer Control and the Information Service of the National Cancer Center. The content of the transcribed interviews was analysed using the constant-comparative method of the grounded theory technique. All transcribed interviews and coding schemes, as initially developed by the primary author, were shared with other project members.

**Results:** It was found that seven out of the eighteen participants did not use their public library to seek information on cancer. Based on past experience, their perception was that such a venue was not the place to find the information they sought. Recently, as mentioned above, an increasing number of libraries have set up a section for health and medical materials, in response to the increasing demand for health-related topics. The findings indicate that libraries need to better inform the general public and patients, once they have initiated a full range of health and medical

information services, in order to change the public perception. Among the 11 participants who had visited their local library to seek information, one reported that she found no information, six found a little and three found some. Only one participant reported that she found all the advice she was looking for. Most respondents reported negative experiences regarding their searches, including outdated medical books, incomprehensible shelving arrangements, unavailability of free booklets and brochures with up-to-date medical information for patients, lack of access to information on rare cancers, the inclusion of books without scientific evidence and limited medical book collections in small regional libraries. These findings demonstrate that there exist many barriers for patients who seek information to cope with their illness.

**Implications:** Based on our findings, we propose the following recommendations for future health and medical information services in Japanese public libraries:

- Promote health and medical information services to patients,
- Provide access to book-lending services without human interaction,
- Develop a strict acquisition policy to offer only high-quality medical books,
- Acquire new books and withdraw outdated publications, and collect free booklets and brochures to provide up-to-date medical information,
- Add e-books to medical book collections,
- Provide access to information on rare cancers,
- Arrange books on shelves so that they are readily locatable by users,
- Predict users' future needs and navigate them to potential information sources,
- Collaborate with hospital libraries to support reference and referral services,
- Help improve the health literacy of local community members, and
- Expand inter-library collaboration to improve access to medical books and information for rural patients.

**Limitations:** The findings and proposals of this study may only be applicable to those who wish to learn about their disease in order to make informed decisions. They may not be applicable to passive patients in their medical decision-making or to those with illnesses other than cancer.

## 5. Abstract:

Japanese public libraries have begun to offer health and medical information services to support users with health-related problems. By combining a survey with follow-up interviews with 18 cancer patients and one family member, this study examines 18 of the participants' perceptions of public library services, their usage of libraries for medical information seeking and the implications of these findings for such institutions in Japan. We found that seven respondents did not use public libraries, because their perception was that they did not fit their information needs. Meanwhile, 11 used libraries to look for patient reports and/or medical information. Many complained of barriers, including outdated materials and incomprehensible shelving systems; however, two respondents, who were heavy users of public libraries, praised the health and medical information service for its availability of new books and brochures on cancer, as well as the inter-library loan service for enabling the location of books not held in their library's collection. Based on the findings, we suggest that libraries promote their health and medical information services to non-users of these venues who are also patients, by creating links of the library to

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websites that are popular among patients. In addition, they should acquire new medical books and brochures and withdraw outdated ones; offer book delivery services through their online public access catalogue; expand inter-library collaboration to make health and medical information resources accessible to local users; offer health literacy training for local community members; and increase their medical e-book collections.

### **References**

Health Information Committee, Japan Library Association. (2014). A Report on Public Library Trends in Offering Health and Medical Information Services. (In Japanese.)