

Archiving Narratives by people living with illness in public libraries in accessible and useful ways for citizens; a case study of Tobyoki Bunko" in Japan.

Yuhei Suzuki

yuhei.suzuki@awai.jp.net

Brief history of tobyoki (闘病記) in Japan

Definition

Narratives written by those who have illnesses or their families that describe process of fighting against/living with diseases (Kadobayashi [2011])

1920s Origin: Essay by a proactive tuberculosis patient

Late 1970s~ Increase in publication of tobyoki in Japan

- Popularization of publishing by word processor and computer
- Trend of sharing personal history
- Major increase in chronic disease

Late 1990s~ Health care providers also became interested in tobyoki

- Notification of disease and informed consent
- Narrative Based Medicine (NBM)

2007~ Over 100 (sometimes over 200) publications every year

Meanings and benefits of tobyoki

For authors

- Leaving advices to peers and opinions to medical systems
- Caring themselves by writing their own feelings and thoughts
- Giving new meanings to experiences and reconstructing themselves
- Grief works for bereaved families

For readers

- Learning from authors' experiences about diseases
- Think about and decide "what I do" and "how I live" by comparison
- Connecting peer patients and making communities

For schools and communities

- Used in seminars and workshops for citizens
- Used as learning materials in medical and nursing schools

Problems in public library

Not in classification rule Tobyoki doesn't have the unique category in Japanese library classification rule. Most were sorted in essay or medicine category

Hard to search by disease Covers and belly bands are taken off in library. Often titles don't contain disease name. Visitors cannot easily what they search for.

Overlooked by librarians Tobyoki was one between specialized medical journal and home medical guide. Neither medical school library nor local community library actively collected tobyoki.

Each one needs to find tobyoki writing about the same disease of them. But, library classification system in Japan didn't meet their needs.

Archiving Tobyoki for citizens

"Paramedica"

Online secondhand bookstore focusing on tobyoki, founded by Fumio Hoshino in 1998

"Health information Bookshelf Project"

Called by Yasushi Ishii in 2004, Hoshino worked with librarians and researchers to develop shelves of tobyoki in library.

1st "Tobyoki Bunko"

- Opened in 2006 at Tokyo Metropolitan Library
- Featured space, unique bookshelf for tobyoki
- About 1,000 tobyoki were sorted by diseases

Nationwide deployment

- 140-200 libraries opened Tobyoki Bunko
- Open, free guideline to develop Tobyoki Bunko
- Media(TV, Newspaper) reported news

&

Digital archives of tobyoki on internet

"Tobyoki Library"(-2020), visual database archiving information of 700 tobyoki, sorted by 12 disease categories

Improvement in search engine of National Diet Library

- National Diet Library modified their archiving policy (June, 2007)
- NDL enabled "NDL-OPAC" users to search books by tobyoki category
- They can also search tobyoki by each disease e.g.)type "tobyoki AND born tumor" on NDL-OPAC

From June 2007 – September 2020
2047 tobyoki, 362 diseases were given data on NDL-OPAC

Issues today about tobyoki and archiving

- Diversification of media: blog, audio, movie, illustration, not only book
- Diversification of narratives by patients: not only fighting against(闘病) disease, patients conduct research on disease and themselves
- Diversification of disease/illness/disability: developmental disorders, contested illnesses
- Cross-disability

Diversification of narratives and process of that made and published

How should we archive narratives(including tobyoki) to meet citizens' various needs?

Reference :

- Ishii, Y. 2005 [Emergence of Tobyoki Bunko] Tobyoki Bunko no tanjo – tobyoki wo hitsuyo na hito ni todokeru kokoromi, Minna no Toshokan 2005.9(in Japanese)
- Ishii, Y. 2020, [Accessibility of tobyoki by disease name, research in National Diet Library] Tobyoki no byomei kara no akusesu no kanousei – kokuritu kokkai toshokan no chosa wo chusin ni, Mita Society for Library and Information Science 2020 Conference (in Japanese)
- Kadobayashi, M. 2011, [Sociology of tobyoki of cancer] Gan tobyoki no shakaigaku ikiru chikara no minamoto ni, Seikaisha (in Japanese)
- Health Information Book Project 2006, "Guideline for developing Tobyoki Bunko", Health Information Book Project (in Japanese)
- Suzuki, Y. 2023, "Digital Archives of Tobyoki (patient narratives) in Japan", SOKOU, 5:31-50 (in Japanese)
- Hoshino F. 2012 [What an owner of tobyoki bookstore thought after diagnosed as cancer] Tobyoki senmon shoten no tenshu ga gan ni natte kangaetakoto, Sankei Shinbun Shuppan (in Japanese)
- Wada E. 2006 [What Tobyoki bunko made for patients and healthcare providers] Tobyoki bunko ha kanja iryosha ni nani wo motarasuka – kenko johodana project no tashokushurenkeikatsudo wo toshite, Information and Documentatation 49 (9) :499-508 (in Japanese)