

Cancer patients' narratives on the JPOP-VOICE Website

ウェブサイトJPOP-VOICEにおけるがん
患者の語りの特徴

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Introduction

- Recently, a large amount of autobiographical illness narrative documents or *tobyoki* have been written by people with different kind of illness (Sun, *et al*, 2010). New information technology make it possible to write and read those *tobyoki* on the website easily.

What is JPOP-VOICE



がんと向き合う

体験者、医療者、支援者の声を動画でご紹介します。

VOICE 体験者・医療者・支援者の声	
大腸がん (17) NEW ▶	肺がん (3) ▶
膵臓がん (1) ▶	乳がん (7) ▶
子宮頸がん (1) ▶	卵巣がん (1) ▶
緩和ケア (7) ▶	

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VOICE
2010年6月30日

 「抗がん剤治療中の過ごし方」について癌研有明病院 看護師の横井麻珠美さんにお話しいただきました。 **NEW**

イベント
2010年5月20日

在宅ホスピス協会の「第13回全国大会 in 岐阜」が開催されます。

VOICE **+ plus** [就労問題](#) **NEW**

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体験者、医療者からのメッセージ

JPOP-VOICE

がんと向き合う [トップページへ >>](#)

大腸がん | 肺がん | 膵臓がん | **乳がん** | 子宮頸がん | 卵巣がん | 緩和ケア | イベント | おしらせ

VOICE
乳がん

▶ 体験者
医療者
支援者



山内 梨香さん ①
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盛岡市在住。2005年末、32歳のときに乳がんと診断される。手術後、骨と肝臓に転移するも、抗がん剤、放射線治療、ホルモン療法を経て、順調に回復(その後の経過は[こちら](#)をご覧ください)。現在は仕事にも復帰し、看護師として患者さんの身体と心のケアにあたりている。2008年に自らの闘病体験をつづった『[がけっぶちナース がんとともに生きる](#)』が2009年3月に飛鳥新社より新装刊。ブログ:『[生きてる喜び日記](#)』



山内 梨香さん ①
(やまうち・りか)

- 石ころのようなしこり
- 悲しすぎる現実
- 術後の治療
- 放射線治療に通う
- 2度目の抗がん剤治療
- 自分の治癒力を信じる
- すべてが巡り合せ
- 弱り目にたたり目一痛

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1 石ころのようなしこり

「乳がん」になる半年ぐらいい前(2004年秋)に、胸に痛みを感じて乳腺外科の先生の所に行ったのですが、そのときにしこりがマンモグラフィではみつからず、『30歳を過ぎるとホルモン(エストロゲン)のせいでも痛くなることもある』と言われて、それで少し様子を見ていました

半年後の春、しこりが“こりっ”とその痛かった場所に来ていたのです。うちの彼がみつけて『何かあるよ』ということで触ってみると、本当に石ころのように硬いしこりが触れました。『それは、おかしなところのしこりだから、おそろしいです』と、おそろしい病院に

Purpose

- The purpose of the present study was to clarify the content and structure of the website “JPOP-VOICE” and propose its usefulness for nursing education as narrative educational documents proposed by Kodaira and Ito (2009).

Method

- The website “JPOP-VOICE” consisted of two main themes; cancer and schizophrenia. The present study analyzed narratives in the area of cancer; large bowel cancer (9 male, 5 female), breast cancer (6 female), lung cancer (2 female), cervical cancer (1 female), and ovarian cancer (1 female). Totally narratives of 24 cases were analyzed by using a text mining software (*Text Mining Studio Ver. 3.2*). We conducted (1) basic statistic analysis, (2) word frequency analysis, (3) word network analysis, and (4) attribute-word relation analysis, including correspondence analysis. We analyzed content words only and excluded function words.

Results: Overall statistics

- The text of narrative of 24 cases was transcribed for the format of the software. The total amount of number of topics was 467. The mean size of one topic was 196.4 characters. The total number of sentences was 3,989. The mean number of characters of each sentence was 23. There were 6,122 types of words in 36,263 total words.

Word frequency analysis

- From the word frequency analysis, the most frequently used words were “*self*” “*Doctor*” “*cancer*” “*surgery*” “*person*” “*go*” “*good*” “*cool*” “*hospital*” “*say*” “*go out*” “*feeling*” “*sensation*” “*pain*” “*do*” “*drink*” “*disease*” “*painful*” “*think*” “*exist*” “*family*” etc. Network analysis revealed the most frequent words associated with “*Doctor*” were “*say*” “*go*” “*listen*” “*mention*” and “*diagnose*”.

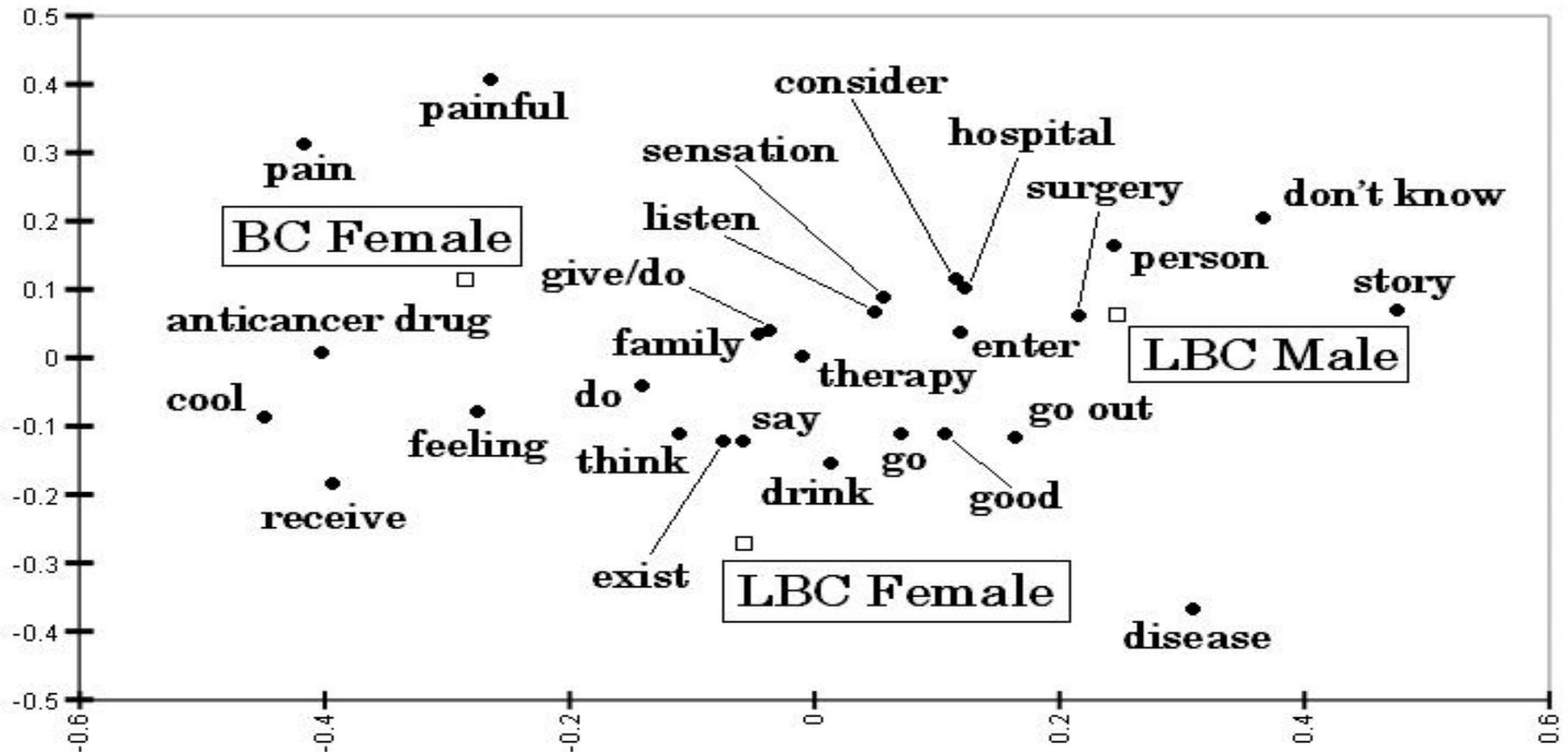
Attribute-word relation analysis: Gender

- According to attribute-word relation analysis, male patients tend to mention about economic topics and work topics, while women used more family-related words than men. Women used the word “*sugoi* (cool)” more frequently than men.

Attribute-word relation analysis: Gender-disease interaction

- Attribute-word relation analysis with gender-disease name interaction showed that, large bowel cancer male patients frequently used the words related to *surgery*, while breast cancer and large bowel cancer female patients tend to use the words related to *medicine (or pills)*.

Fig. 1 The relationship between gender, cancer type (BC as breast cancer; LBC as large bowel cancer), and frequent words.



- Fig. 1 shows the relationship between gender, cancer type (BC as breast cancer & LBC as large bowel cancer), and frequent words.

Conclusion

- Sun *et al* (2010) analyzed the narrative of schizophrenia patients in “JPOP-VOICE” and found that their text includes words related to the way to take medicine and to manage the symptoms of the illness and to keep social support, while they mentioned less about their doctors. Our results were contrastive to this previous study, because the cancer patient often mentioned about their doctors. That seemed to reflect the difference of the meaning of being a schizophrenia patient vs. a cancer patient. People with schizophrenia are more community-oriented while cancer more medical treatment- oriented.

Websites as narrative documents

- The aim of this website is directed to patients and their family members in order to reduce anxiety about the disease and to increase the courage to face it through motion pictures and voices of real people with the disease as well as medical advice of professionals. Like reading autobiographical illness narrative documents such as published books written by patients, the websites of illness narratives such as “JPOP-VOICE” and DIPEX-Japan, are rich in the knowledge and experiences of which the nurses cannot be aware in their dairy direct practices (Kodaira & Ito 2009).

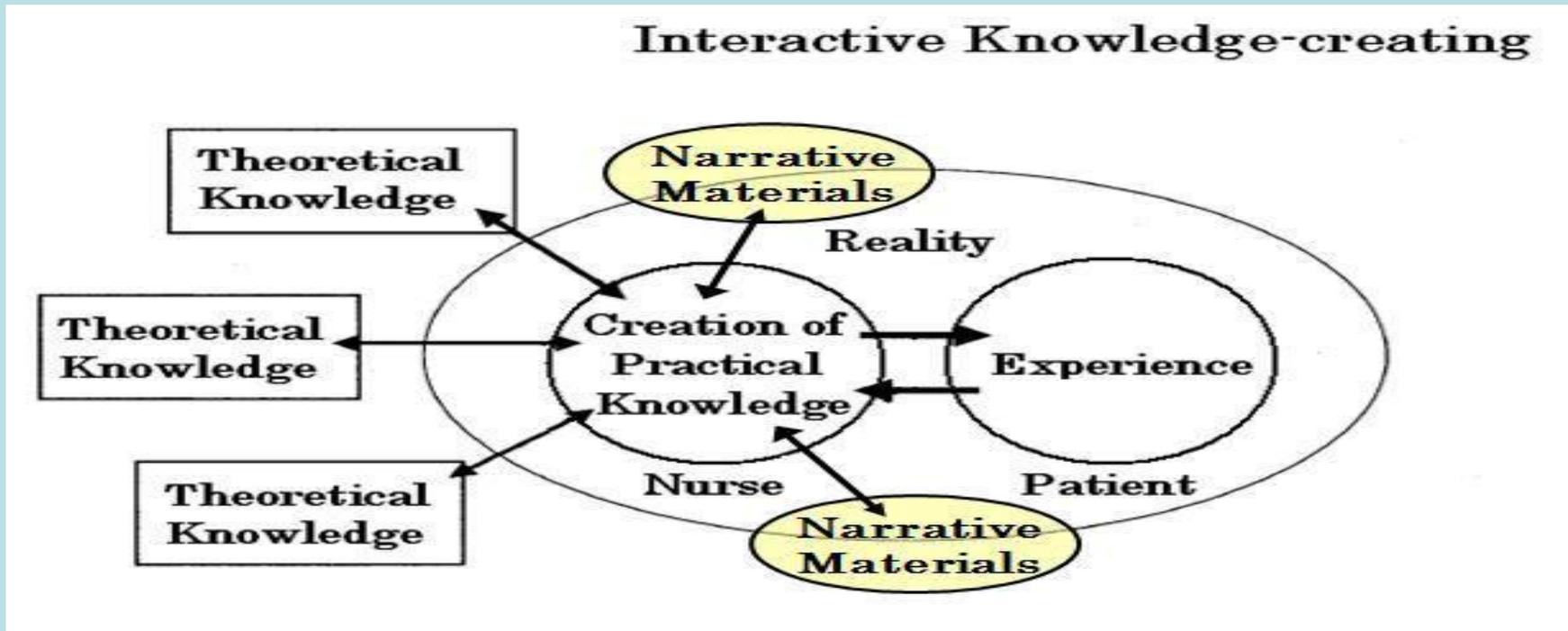
Websites used for nursing practice and education

- These websites can be utilized for the mental health nurses and nursing students to better understand their suffering, healing and human conditions by indirect experience to listen to their .
- Kodaira & Ito (2010) pointed out that websites of illness narrative includes non-systematic individual weblogs and systematic sites run or supervised by medical professionals.

A website of self-help studies by people with mental illness

- One of the systematic sites of mental illness narratives is “*Tojisha Kenkyu no Heya* (The room of self help studies)” run by Urakawa Bethel House, which contains various examples of illness narratives of problem behaviors collectively discussed by people with mental illness with assistance of mental health professionals (see Otaka, Ito & Kodaira, 2010).

Fig. 2 Narrative materials as the third resource of nursing knowledge



- Nakayama (2004) proposed a model of nurses' knowledge structure, which suggests two kind resources of practical knowledge; the theoretical knowledge and the knowledge based on their experience in the real world. We might add narrative educational materials as the third source of practical knowledge for nursing as shown in Fig 2.

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