TEXT MINING ANALYSIS OF THE NARRATIVES OF A PATIENT WITH FIBROMYALGIA FOCUSING ON EXPRESSIONS OF PAIN

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Emerald Hotel, Bangkok PS II-42 16th EAFONS
The main symptoms of Fibromyalgia (FM: 線維筋痛症) = widespread pain of unknown causes

Estimates of FM patients in Japan:
# more than 2 million patients
# 1.66% of the population
# 80% are female

- Difficult to diagnose through clinical testing
- Low awareness among medical practitioners
- No definitive treatment, except for symptomatic treatment such as reducing pain
Purpose

- To understand how a patient with fibromyalgia thinks, feels, and behaves
- Based on an analysis of a patient's blog entries
Methods

Text: “Satoko Hayase's Fibromyalgia Journal”
Website of 505 entries (14 January 2008 - 23 July 2012)

- Diagnosed with FM at 18 years old, now 26
- In order for readers to understand pain and anguish caused by FM
Data Analysis

• The journal and blog were analyzed with text mining software
  (Text Mining Studio version 4.1)

1. Overall word frequency analysis

2. Yearly change of the use of words
Results 1. Basic information
- The total number of entries: 505 pages
- The average number of characters in each article: 163.4
- The average characters in a sentence: 13.4
- Word types: 5,720
- Words in total: 32,720

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<td>47</td>
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Results 2.

Total word frequency

- pain (655)
- painful (485)
- side effects (360)
- think (思う) (253)
- live (241)
- fibromyalgia (164)
- use (161)
- need / be (144)
- life (199)
- opioid (118)
- myself (116)
- severe pain (110)
- think (考える) (109)
- person / people (107)
- feeling (101)
- understand / don't understand (97)
- medication (94)
- talking (93)
- my body (91)
- words (90)
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Results 3. Pain and agony

• “pain” (#1) + “painful” (#2): 1,140 (36.8%)
• Plus “severe” (#8)/“throbby” (#19) pain: 1,318 (42.5%)
• The frequent occurrence of pain-related words
• Predominance of painful experiences of fibromyalgia in the narrative
Results 4. From *painful* to *pain*

- 2008 (first year): “*painful*”
- 2009 (second year): “*pain*” and “*side effects*”

- From *direct* experience of pain *here and now*
- To *strategies for coping* with pain and medicine
Conclusions

- FM is a disease of pain
- Further research on Narrative Based Medicine (NBM) of FM is needed (as well as EBM)
- Fibromyalgia should be more clearly recognized by:
  1) the medical community
  2) society in general