POSITIVE PAIN COPING
OF A PATIENT WITH
FIBROMYALGIA
A TEXT MINING ANALYSIS OF BLOG

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Poster Session  II-S-067   The 3rd IPPA
Westin Bonaventure Hotel, LA, USA
Background

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
Method

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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| total pages | 505 |
Results 2.

Top 20 words by 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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**total in each year**

853 1536 292 211 207 3099
Results 3. Pain and agony

- “pain” (#1) + “painful” (#2): 1,140 (36.8%)
- Plus “severe” (#8)/“thronbing” (#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