

POSITIVE PAIN COPING OF A PATIENT WITH FIBROMYALGIA

A TEXT MINING ANALYSIS OF BLOG

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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

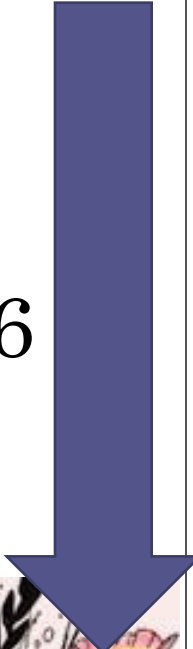
Text: “**Satoko Hayase's Fibromyalgia Journal**”

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**

早瀬さと子の線維筋痛症闘病記

18歳で線維筋痛症と診断され、
オピオイドで痛みを抑えている日々の命の記録。
線維筋痛症、周りの不理解、
その苦しみと、その激痛を少しでも知って下さい。



Data Analysis

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

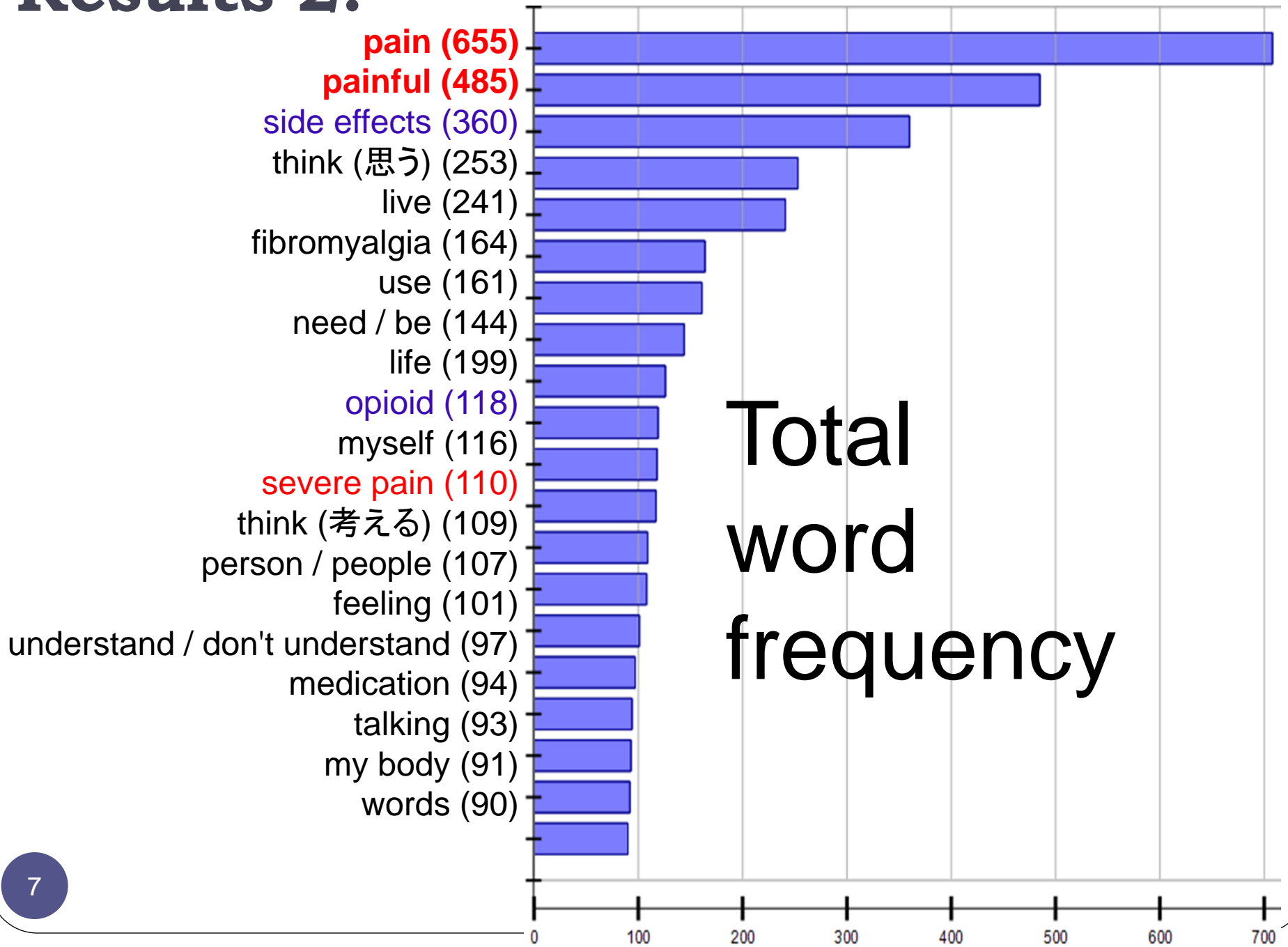
1. Overall word frequency analysis
2. Yearly change of the use of words

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

year	entries
2008	122
2009	204
2010	85
2011	47
2012	47
total pages	505

Results 2.



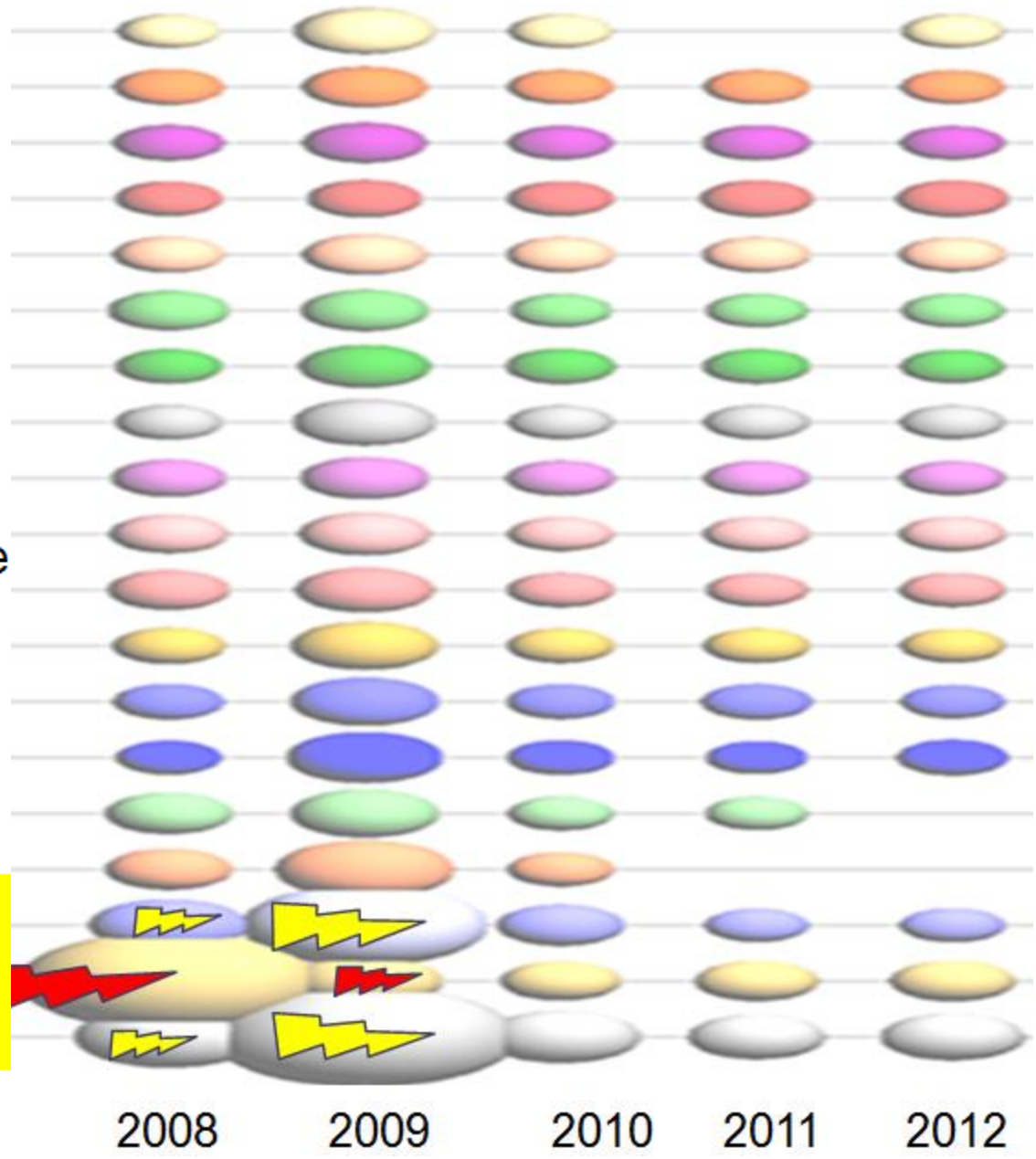
#	単語	word	part of speech	2008 (y)	2009 (y)	2010 (y)	2011 (y)	2012 (y)	SUM
1	痛み	pain	noun	133	313	89	55	65	655
2	痛い	painful	noun	303	83	29	34	36	485
3	副作用	side effects	adjective	89	221	40	4	6	360
4	線維筋痛症	fibromyalgia	noun	39	118	7	0	0	164
5	命	life	noun	39	72	6	2	0	119
6	オピオイド	opioid	noun	7	85	10	1	15	118
7	自分	myself	noun	14	72	11	15	4	116
8	激痛	severe pain	noun	17	71	9	8	5	110
9	人	person / people	noun	33	56	9	2	7	107
10	薬	medication	noun	26	46	6	8	8	94
11	身体	body	noun	22	42	13	7	6	90
12	言葉	words	noun	9	64	5	7	5	90
13	ドクター	doctor	noun	9	47	13	10	4	83
14	神様	God	noun	32	41	2	2	3	80
15	良い	good	adjective	15	35	11	11	8	80
16	ベッド	bed	noun	9	22	9	18	18	76
17	ブログ	blog	noun	15	35	6	12	5	73
18	感じ	feeling	noun	14	36	7	7	4	68
19	疼痛	throbbing pain	noun	2	61	3	0	2	68
20	目	eyes	noun	26	16	7	8	6	63
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)/ “**throbbing**” (#19) pain: 1,318 (42.5%)
- The frequent occurrence of **pain-related words**
- Predominance of **painful experiences** of **fibromyalgia** in the narrative



疼痛	throbbing
感じ	feeling
ブログ	blog
ベッド	bed
良い	good
ドクター	doctor
言葉	words
身体	body
薬	medication
人	person / people
激痛	severe pain
自分	myself
オピオイド	opioid
命	life
線維筋痛症	fibromyalgia
副作用	side effects
痛い	painful
痛み	pain



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

