

# Patient Experience in Online Support Forums: Modeling Interpersonal Interactions and Medication Use



Annie T. Chen

atchen@email.unc.edu

University of North Carolina, Chapel Hill

## BACKGROUND

Online support groups (OSGs) play an important role in the lives of people all over the world, who suffer from many different conditions. Not only are OSGs a source of support, they also provide information about how to manage one's illness.

But there is a great deal that we do not yet know about the kinds of experiences that patients discuss on OSGs. Here we explore two important aspects:

- To what extent do emotions appear along with important figures in discussion forums?
- How do patient experiences vary with phases of medication use?

## METHODS

### Corpus

- Aggregated through a series of focused crawls of an online social networking site
- ~3.5 years of discussion content

### Emotion Identification using WordNet-Affect

Emotion	Example
Anger	I'm happy but also <b>mad</b> cuz I've been suffering and no doctor bothered to tell me about this.
Fear	I have the prescription right here and <b>afraid</b> to try it.
Frustration	It is extremely <b>discouraging</b> to hear that repeatedly...
Sadness	It's <b>sad</b> that I am so excited about getting some sleep.
Anxiety	You may be <b>worrying</b> over nothing.
Happiness	I'm so <b>happy</b> Lyrica is working for you.
Hope	I really <b>hope</b> this works for you.

### Identification of Phases of Routinized Medication Use

Phase	Rule	Example
Start	"start", "began"	I started Lyrica about 4 months ago and I have gained about 10 pounds.
Stop	"stop", "off" or "quit"	Hi, I am weaning off of Lyrica as it had no effect on my fibro and some nasty side effects.
Current	"I take", "is working", "currently", "been on" etc.	I've been taking Lyrica for about a year and it really works for me.
Switch	Fulfills both start and stop criterion or contains "switch".	My doc is weaning me off Lyrica and wants to start me on Savella.
Transition	A: "initially", "at first", "in the beginning" B: "after", "but", "then"	Lyrica made me feel better at first, but then within 2-3 days I needed more to feel well, then more after that.

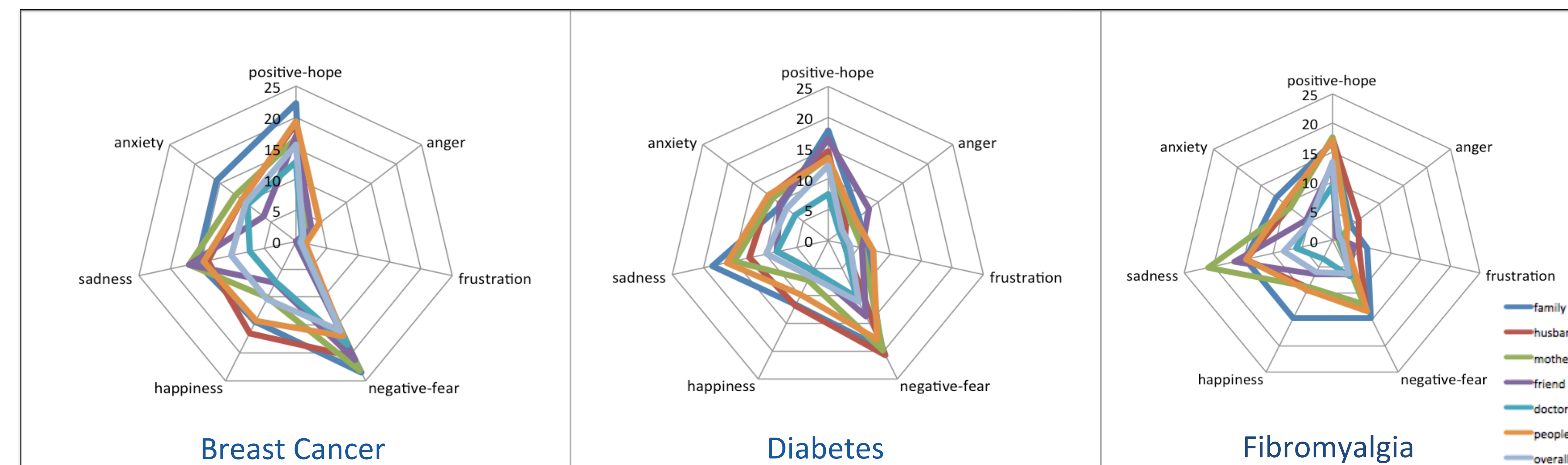
## PART 1

How frequently do important figures appear in conversation?

Term	Breast cancer	Diabetes	Fibromyalgia
Family	5.09	3.95	1.75
Husband	4.03	3.4	3.02
Wife	0.57	0.92	0.41
Mother	8.62	3.86	1.54
Son	1	3.86	0.61
Daughter	2.23	4.8	1
Friend	3.13	2.23	1.85
Doctor	13.28	13.49	16.42
People	8.42	13.37	8.96

Greater presence of mothers in breast cancer, sons and daughters in Type 1 diabetes, and doctors in fibromyalgia

To what extent do emotions come up when these people are mentioned?



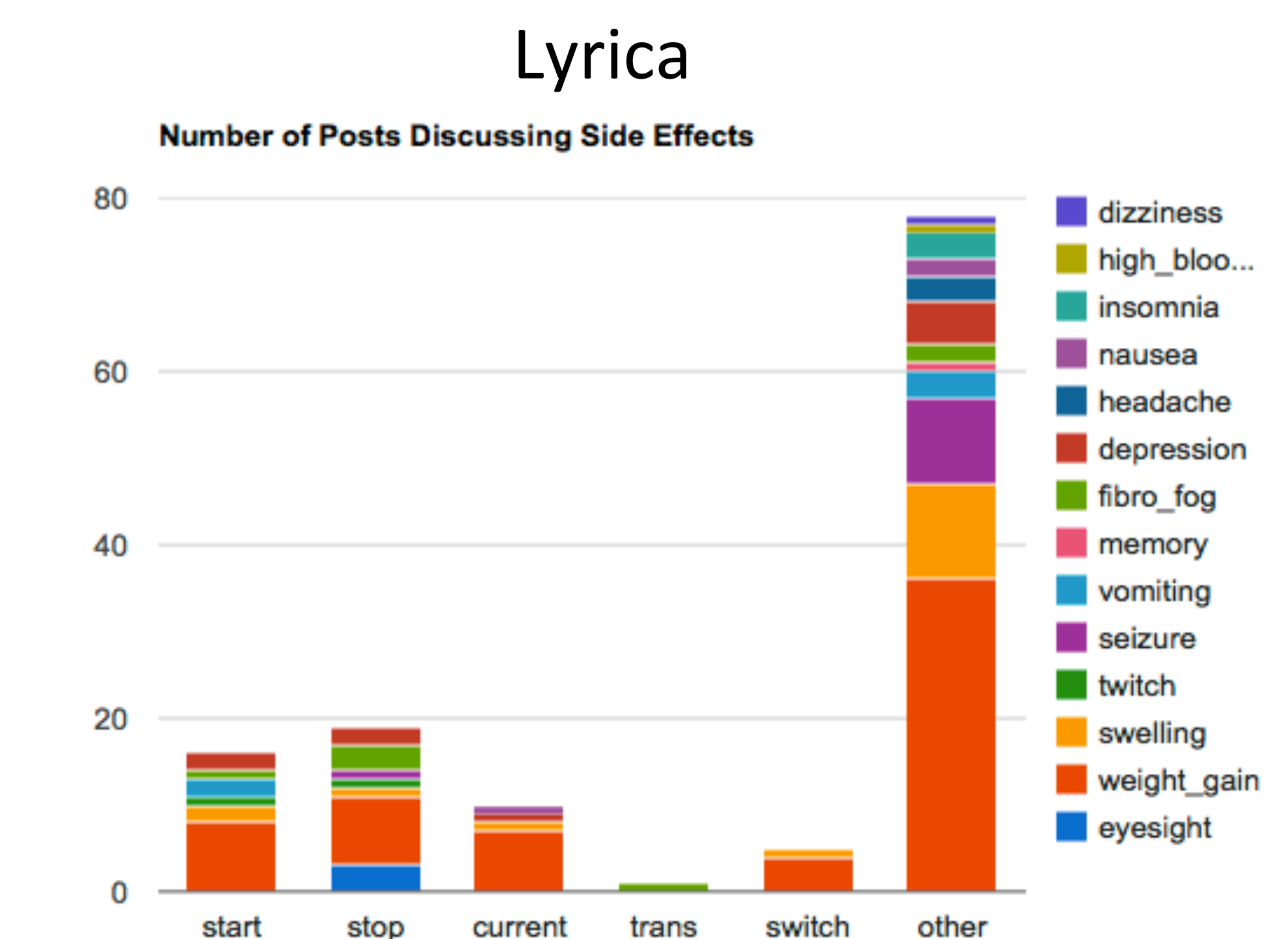
- Greater expression of affect in breast cancer overall
- Levels of affect were lowest in posts that mentioned doctors

## DISCUSSION

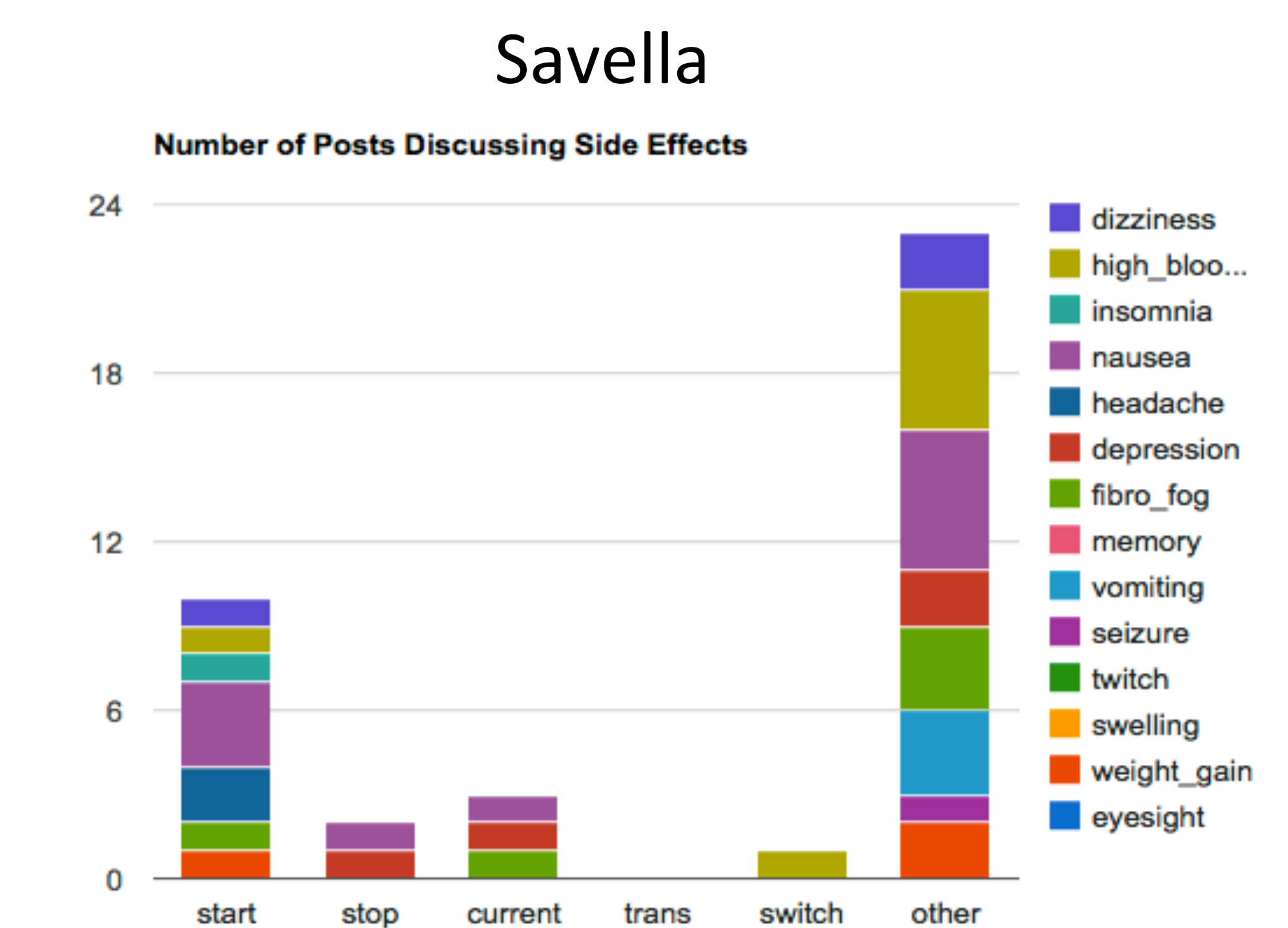
- Emotional expression varies depending on the condition and the people that are mentioned in health discussions
- Understanding this affect can be invaluable for designing forums that are better fulfill patients' support needs, as well as designing support mechanisms in offline environments

## PART 2

What side effects do patients experience at different phases in medication use?



Common side effects include weight gain



Common side effects include nausea and high blood pressure

## DISCUSSION AND FUTURE WORK

- Medications have different "signatures"
- Less frequent, but more severe side effects such as vision loss (Lyrica in stop phase) are not lost in a sea of posts
- Examine other aspects of patient experience at different phases of medication use

## ACKNOWLEDGMENTS

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