Longitudinal analyses of virtual events and online engagement in a peer support online health community for adolescents and young adults with chronic illnesses

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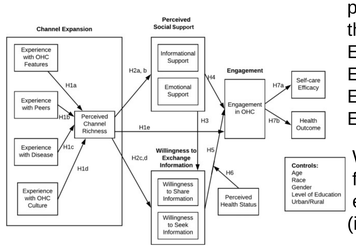
INTRODUCTION

Online health communities (OHCs) can be a significant source of social support and community for people living with chronic illnesses.

OHCs struggle with maintaining engagement and sharing of experiences by members over time in digital spaces, as most users in social media channels are categorized as short-term “lurkers”.

Channel Richness Theory Posits that OHC engagement is driven by perceived channel richness of the OHC, made up of Experience with features, Experience with peers, Experience with disease, and Experience with OHC culture.



We operationalize these channel features as daily, seasonal events, and daily active users (including volunteers and staff).

The aim of this project is to use multi-level modeling to assess the impacts of staff-moderated daily events, seasonal events, and total number of active users on patient engagement, measured by daily comments for patients enrolled in the Streetlight Gaming and Online Team Discord server.

METHODS

- **Channel Richness Predictors** (IVs):
  - Day-specific events being offered by Streetlight program volunteer, staff, or patients (Binary outcome by day)
  - Seasonal events offered by Streetlight program staff and volunteers
  - Number of active users per day (including volunteers and staff), number of total users in server (binary outcome by day)
  - Years since joining Discord, centered on when each patient first joined the server
- **OHC Engagement Outcomes** (DVs)
  - 662 snapshots of daily comment totals (from January 2019-January 2022) for patients in Discord, totaling 15,312 comments. (Days missing = 428).
  - We will only analyze patient comments for these analyses, from patients who have not died during their enrollment in SGL (n =84). Covariates
  - Further analyses are planned to assess differential engagement trajectories within the population of end-of-life patients (n=14), who contributed 1,220 comments to the server.
- **Covariates:** Gender, Diagnosis, Age

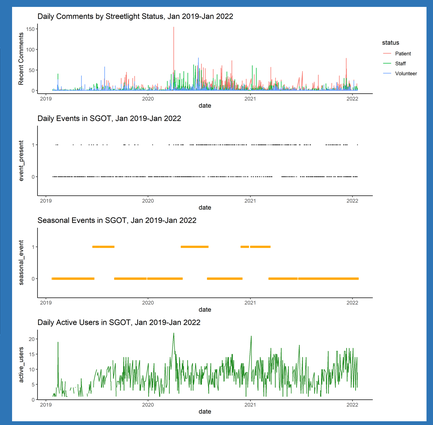
Analysis: 6 sequentially-built growth models using *R’s lme4* package for multi-level linear regression utilizing MLE parameter estimation.

- 1. Unconditional means, 2. unconditional growth, 3. Individual patient characteristic level data, 4. Conditional Growth with daily event, interaction with time, 5. Conditional growth with seasonal event int. with time, and daily active players and any previously identified sig. terms
- Random effects: we allow individual patient slopes of daily comments to vary randomly over their years in Discord.

Model Formulas:

1. $Recent\_Player\_Comments_{ti} = \beta_{00} + r_{0i} + e_{ti}$
2. $Recent\_Player\_Comments_{ti} = \beta_{00} + \beta_{10}*Days\_Since\_Joining\_Discord_{ti} + r_{0i} + r_{1i}*Days\_Since\_Joining\_Discord_{ti} + e_{ti}$
3. $Recent\_Player\_Comments_{ti} = \beta_{00} + \beta_{01}*Diagnosis + B02*Gender + B03*Age + \beta_{10}*Years\_Since\_Joining\_Discord_{ti} + r_{0i} + r_{1i}*Years\_Since\_Joining\_Discord_{ti} + e_{ti}$ 4. *Daily Event*
4. $Recent\_Player\_Comments_{ti} = \beta_{00} + \beta01*Daily\_Event + \beta_{10}*Years\_Since\_Joining\_Discord_{ti} + \beta_{11}\ Years\_Since\_Joining\_Discord_{ti}*Daily\_Event + \ r_{0i} + r_{1i}*Years\_Since\_Joining\_Discord_{ti} + e_{ti}$
5. $Recent\_Player\_Comments_{ti} = \beta_{00} + \beta_{01}*Seasonal\_Event + \beta_{10}*Years\_Since\_Joining\_Discord_{ti} + \beta_{11}\ Years\_Since\_Joining\_Discord_{ti}*Seasonal\_Event + \ r_{0i} + r_{1i}*Years\_Since\_Joining\_Discord_{ti} + e_{ti}$
6. $Recent\_Player\_Comments_{ti} = \beta_{00} + \beta_{01}*Daily\_Event + \beta_{10}*Years\_Since\_Joining\_Discord_{ti} + \beta_{11}\ Years\_Since\_Joining\_Discord_{ti}*Daily\_Event + \beta_{02}*Active\_Users + \beta_{12}Years\_Since\_Joining\_Discord_{ti}*Active\_Users + \ r_{0i} + r_{1i}*Years\_Since\_Joining\_Discord_{ti} + e_{ti}$

Online health community virtual events facilitated by hospital peer support program were associated with increased AYA patient daily commenting rates, and continued activity over 3 years.



Link to GitHub repository:
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RESULTS

* Null means/growth model results

- Intercept: patients begin on average commenting .51 per day, with slight negative slope over years in discord (not significant though)
- **Individual covariates**– no significant associations\
- **Daily event fixed effects** significantly increase per patient daily comments by .22
- However, for **each year of Discord , daily events** associated with reduced average comments by .08.
- **Seasonal** events no sig association
- # of **active players** may be key mediator , increases comment rates by .08 per active user, and reduces effect size of daily event (though still significant)
  - Sensitivity analyses show events associated with increase of 1.1 active users, potential to act as mediator
- **Model fit**: Best model fit achieved in final Daily events and active users' model (-13,267 in deviance from initial unconditional means) , though across models, within and between person variance stayed consistent, with a slight increase in patient-level intercept variance. ICCs show large amount of variance coming from individual-level.

Table 1.Characteristics of Streetlight Gaming and Online Team Users

Participant Characteristics (N = 84)	Mean (SD) or N (%) Med (Range)
Total Comments (N=26,284, overall,non-deceased patient comments: n= 15,312 used for analysis)	
Patient	15,312 (58.3%), Avg 168.7 per patient, missing 1220 (4.6%)
Volunteer	3,970 (15.1%), Avg 63.0 per volunteer
Staff	5,782 (22.0%), Avg 963.7 per staff
Daily Comments	
Patient (total	.5 (2.9), 0 [0,155]
Years since joining Discord at end of data collection period	1.2 (.8), 1.1[0, 2.99]
Age	20.8 years (4.2) 20.0 [14.0, 35.6]
Gender	
Female	13 (15.5%)
Male	37 (44.0%)
Non-binary	2 (2.4%)
Missing	32 (38.1%)
Diagnosis	
Autoimmune Illnesses	10 (11.9%)
Cancer	16 (19.0%)
Cystic Fibrosis	15 (17.9%)
Gastrointestinal Illnesses	6 (7.1%)
Sickle Cell Disease	7 (8.3%)
Organ Transplant	19 (22.6%)
Other	11.0 (13.1%)
Deceased	14 (14.3% of overall 98 pt sample)
Missing	1 (1.0%)
Program Daily Events	N= 344 daily events (.3 per day)
Program Seasonal Events	N= 266 days of seasonal events

	Unconditional Means Model			Unconditional Growth			Conditional Day Event Model			Conditional Seasonal Event Model			Daily events and active users model		
Predictors	*Estimates*	*CI*	*p*	*Estimates*	*CI*	*p*	*Estimates*	*CI*	*p*	*Estimates*	*CI*	*p*	*Estimates*	*CI*	*p*
(Intercept)	0.41	0.18 – 0.63	**<0.001**	0.51	0.20 – 0.82	**0.001**	0.43	0.12 – 0.75	**0.006**	0.47	0.16 – 0.78	**0.003**	-0.14	-0.47 – 0.18	0.389
years since discord				-0.18	-0.42 – 0.05	0.117	-0.15	-0.38 – 0.08	0.208	-0.17	-0.40 – 0.07	0.162	-0.22	-0.45 – 0.01	0.066
event present [1]							0.22	0.12 – 0.33	**<0.001**				0.12	0.02 – 0.23	**0.022**
years since discord * event present [1]							-0.09	-0.16 – -0.01	**0.020**				-0.08	-0.15 – -0.01	**0.035**
seasonal event [1]										0.10	-0.03 – 0.22	0.133			
years since discord * seasonal event [1]										0.03	-0.07 – 0.12	0.593			
active users													0.08	0.07 – 0.09	**<0.001**
Random Effects															
σ^2	6.75			5.96			5.95			5.95			6.02		
τ_{00}	1.08 $_{record\_id}$			1.95 $_{record\_id}$			1.95 $_{record\_id}$			1.95 $_{record\_id}$			2.12 $_{record\_id}$		
τ_{11}				0.89 $_{record\_id.years\_since\_discord}$			0.87 $_{record\_id.years\_since\_discord}$			0.89 $_{record\_id.years\_since\_discord}$			0.89 $_{record\_id.years\_since\_discord}$		
ρ_{01}				-0.62 $_{record\_id}$			-0.62 $_{record\_id}$			-0.62 $_{record\_id}$			-0.62 $_{record\_id}$		
ICC	0.14			0.23			0.23			0.23			0.24		
N	83 $_{record\_id}$			81 $_{record\_id}$			81 $_{record\_id}$			81 $_{record\_id}$			81 $_{record\_id}$		
Observations	34680			33792			33792			33792			32632		
Marginal R^2 / Conditional R^2	0.000 / 0.138			0.003 / 0.235			0.003 / 0.232			0.003 / 0.233			0.016 / 0.252		
Deviance	164973.370			156740.928			156718.327			156725.576			151706.741		
AIC	164979.370			156752.928			156734.327			156741.576			151724.741		

DISCUSSION:

- Daily events and number of active users in the Discord server were associated with higher per-patient daily commenting rates
- Effect of daily events on patient daily comments is reduced for longer-term players
- Longevity of engagement in this program is high compared to previous literature on OHCs
- Staff and volunteer presence needed for server moderation and event facilitation
- Further efforts needed to continue to build engagement from long-term patients
- Novel combination of inpatient and virtual outpatient programming could serve as model for other OHCs

ACKNOWLEDGMENTS:

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