



In HCV-Infected Patients, Internalized Stigma and Experienced Stigma are Correlated with Psychological State and Health-Related Quality of Life: Baseline Data from the PROP UP Study



Michael Gelman, MD, PhD^{1,2}, Norbert Bräu, MD, MBA^{1,2,3}, Donna Evon, PhD⁴ and The PROP UP Study Group

(1)Infectious Diseases Section, James J Peters Veteran Affairs Medical Center, Bronx, NY, (2)Division of Infectious Diseases and Division of Liver Disease, Icahn Mount Sinai School of Medicine, New York, NY, (3), Icahn Mount Sinai School of Medicine, New York, NY, (4)Division of Gastroenterology & Hepatology, University of North Carolina, Chapel Hill, NC, United States

Background

- People with hepatitis C encounter **stigma** due to their status¹⁻³
 - **Experienced** or “enacted” stigma (being treated differently by others)
 - **Internalized** or “felt” stigma (effect on identity and self-esteem)
- Hepatitis C-related stigma is associated with:⁴
 - Anxiety
 - Depression
 - Cognitive problems
 - Worse symptoms
 - Less acceptance of illness
- Stigma causes **barriers to care**⁵
- **PROP UP:** a chance to study hepatitis C stigma
 - Study of how **patient-reported outcomes** (PROs) change in the **real world** over course of HCV treatment⁶
 - SSCI-8 (a validated stigma measure)⁷ added to PROP UP battery
- Overall Research Question:
In an era of straightforward HCV cure, what are the correlates of stigma at pre-treatment baseline?

Methods

Stigma Scale: SSCI-8 (NeuroQOL-Stigma)

- 8-item scale with a two-factor structure:
- 2 items measure an **internalized stigma** factor (IntSt)
 - Q16: I felt embarrassed about my illness
 - Q17: I felt embarrassed because of my physical limitations
 - 6 items measure an **experienced stigma** factor (ExpSt)
 - Q21: Some people acted as though it was my fault I have this illness
 - Q04: Because of my illness, I felt left out of things
 - Q01: Because of my illness, some people seemed uncomfortable with me
 - Q02: Because of my illness, some people avoided me
 - Q05: Because of my illness, people were unkind to me
 - Q08: Because of my illness, people avoided looking at me
- Each item has 5 response levels:
Never (1), Rarely (2), Sometimes (3), Often (4), Always (5)

Variables from PROP UP Data Set

- Demographic factors (DFs)**
- Age (continuous)
 - Birth Sex (male vs. female)
 - Race (black vs. nonblack)
 - Employment (working at least part time vs. other)
 - Marital Status (single/married vs. separated/divorced/widowed)
 - Household Income (dichotomized at \$40,000/yr)
 - Education (up to/including HS level diploma vs. higher)

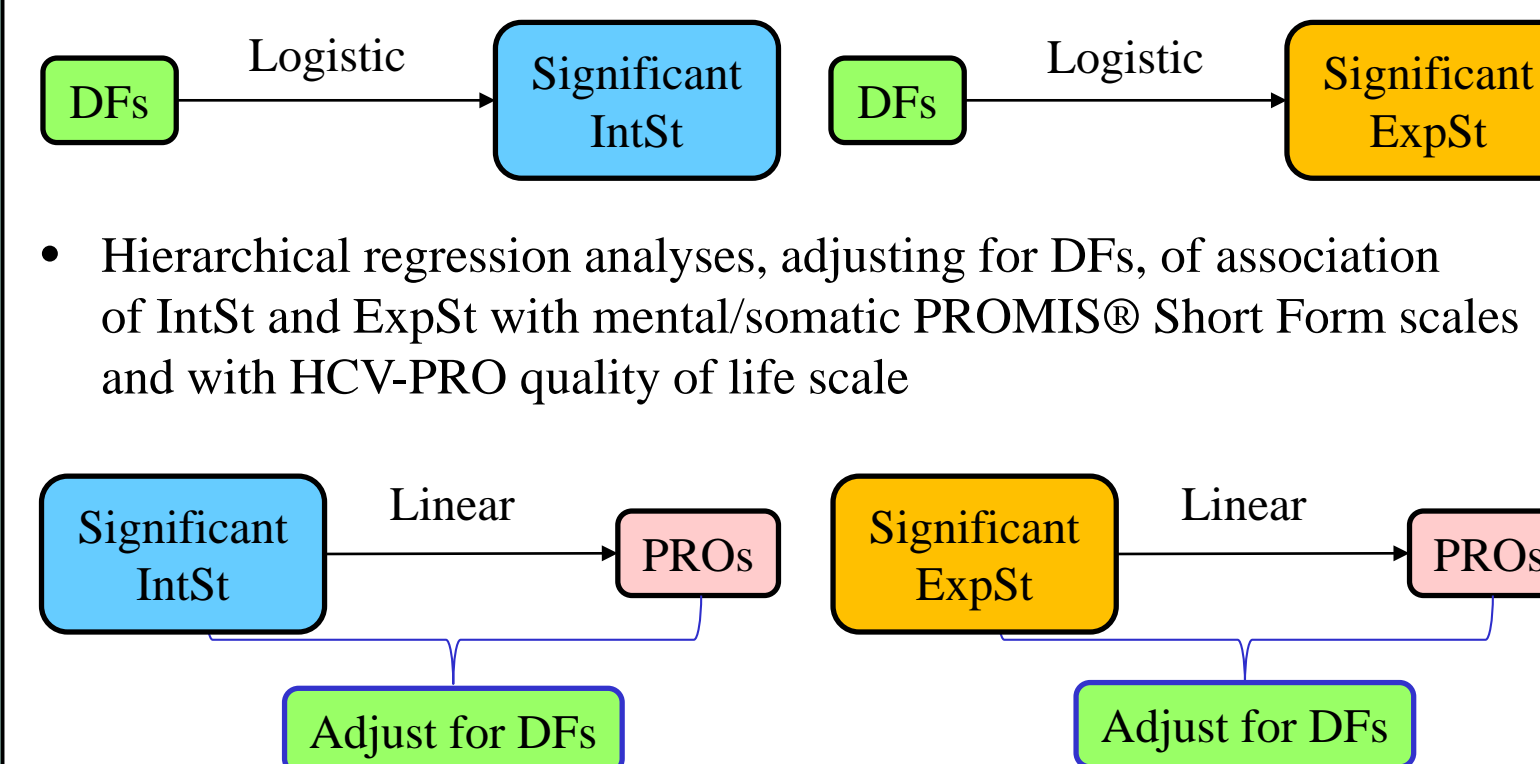
Patient Reported Outcomes (PROs) – all based on 5-point scaled items PROMIS® Short Form T-scores (mean = 50, SD = 10 in general population):
Mental/somatic health patient-reported outcome (PRO) scales

- **Depression-8a** (8 items, higher score = more intense depression)
- **Anxiety-4a** (4 items, higher score = more intense anxiety)
- **Anger-5a** (5 items, higher score = more intense anger)
- **Fatigue-7a** (7 items, higher score = more fatigue)
- **Sleep Disturbance-8a** (8 items, higher score = more disturbed sleep)

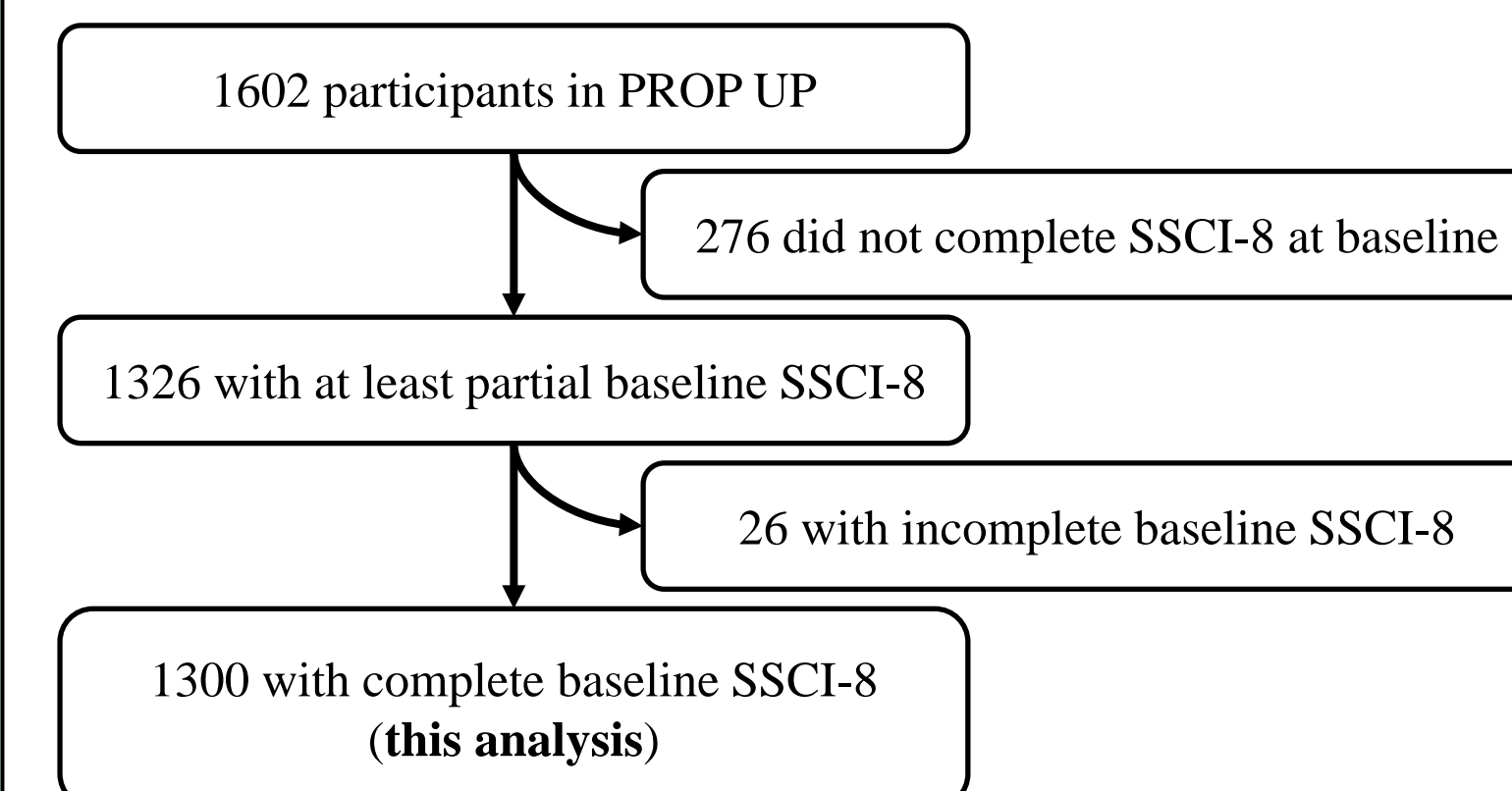
HCV-PRO scale (overall quality of life and functional status, developed to be HCV-specific, 16 items, **higher score = better quality of life**)

Statistical Analyses

- Response frequency histogram of individual items
- Prevalence of **any** stigma (at least one Rarely or higher) on IntSt and ExpSt
- Prevalence of **significant** stigma (at least one Sometimes or higher) on IntSt and ExpSt
- Multivariate regression analyses of DFs associated with IntSt and ExpSt



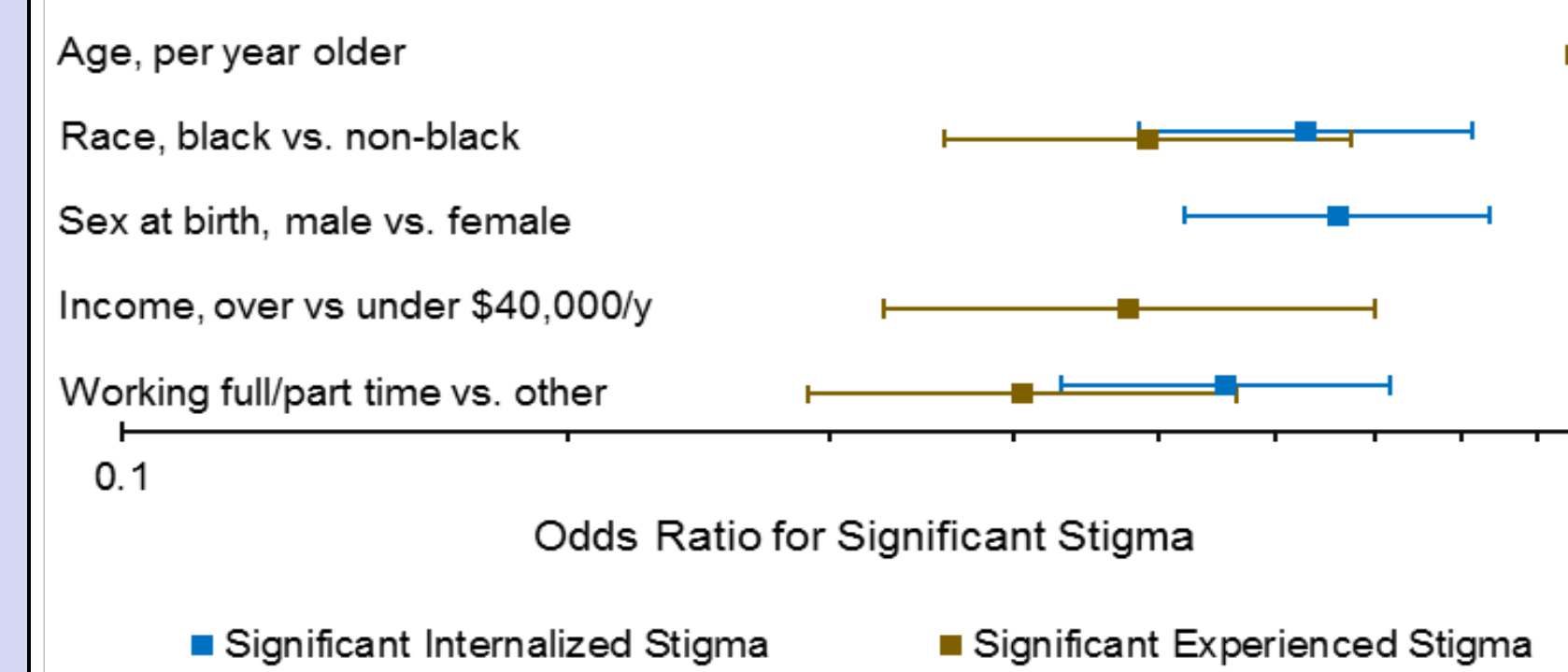
Participant Flow Diagram



Overall Stigma Baseline Prevalence

Baseline Sample (n = 1300)	IntSt (2 items)	ExpSt (6 items)
Normalized scale value per item, mean (SD)	1.90 (1.09)	1.33 (0.64)
Any (any answer at least Rarely), n (%)	724 (55.7%)	505 (38.8%)
Clinically significant stigma (any answer at least Sometimes), n (%)	542 (41.7%)	336 (25.8%)

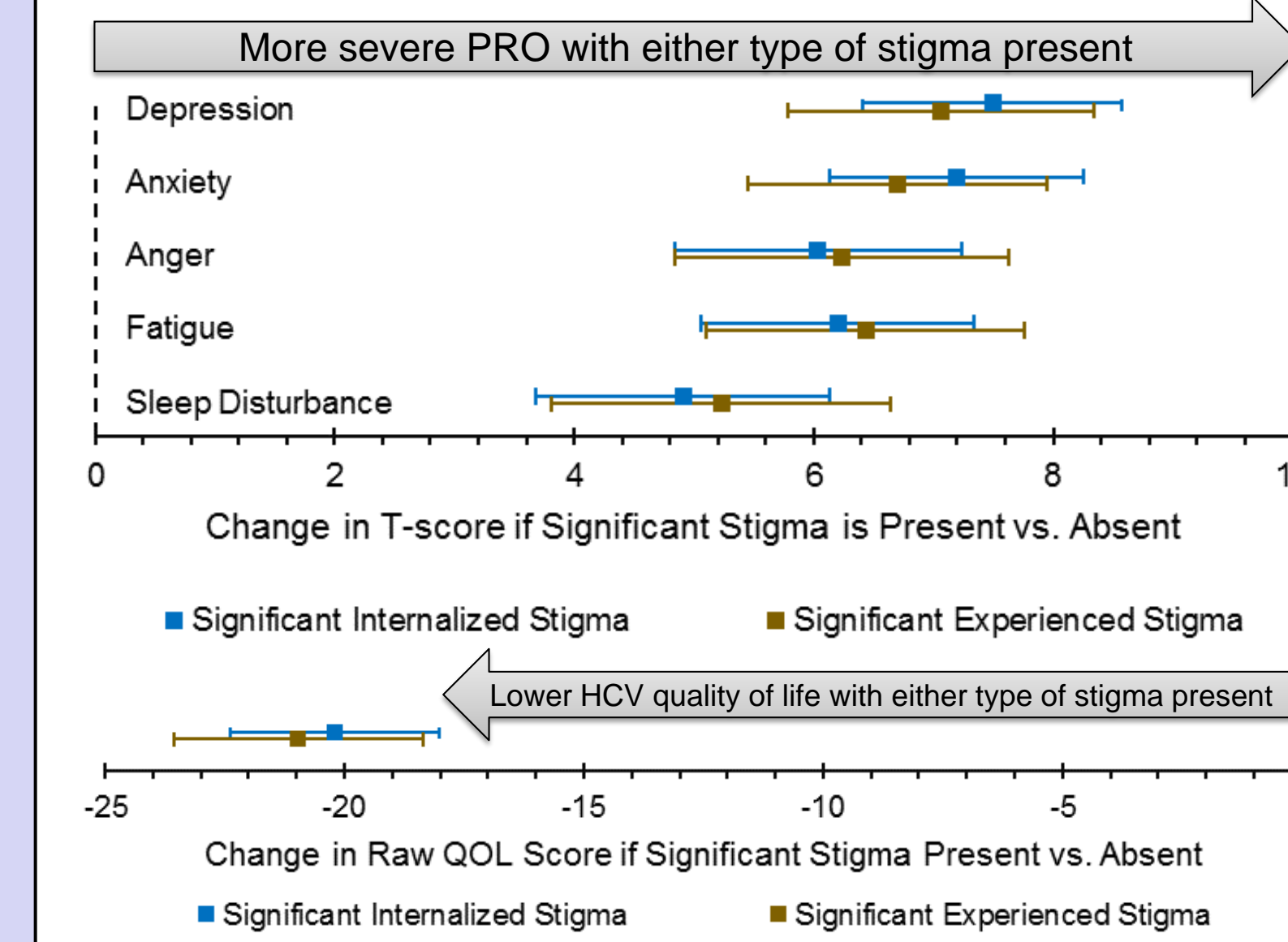
Demographics Associated with Stigma



Multiple Logistic Regression for Clinically Significant Stigma [OR (95% CI)]	Clinically Significant Internalized Stigma (n = 1229)	Clinically Significant Experienced Stigma (n = 1229)
Age, per year	0.971 (0.962, 0.982)	0.957 (0.945, 0.969)
Race, black vs. non-black	0.629 (0.486, 0.815)	0.492 (0.359, 0.674)
Sex at birth, male vs. female	0.660 (0.521, 0.835)	
Income, over vs under \$40,000/y		0.477 (0.326, 0.699)
Working full/part time vs. other	0.555 (0.430, 0.717)	0.405 (0.290, 0.565)

Bold: p<0.001, italic: p<0.01 (all others p>0.05 and excluded from model)

Association of Significant Stigma w/PROs



Dependent Variable	Significant Internalized Stigma (Y/N) as Predictor	Significant Experienced Stigma (Y/N) as Predictor
Depression T-score	7.492 (6.408, 8.575)	7.057 (5.778, 8.335)
Anxiety T-score	7.196 (6.136, 8.256)	6.699 (5.448, 7.949)
Anger T-score	6.036 (4.834, 7.237)	6.242 (4.847, 7.636)
Fatigue T-score	6.201 (5.061, 7.342)	6.434 (5.108, 7.759)
Sleep Disturbance T-score	4.909 (3.684, 6.135)	5.231 (3.813, 6.648)
HCVPRO Quality of Life	-20.20 (-22.38, -18.01)	-20.97 (-23.57, -18.36)

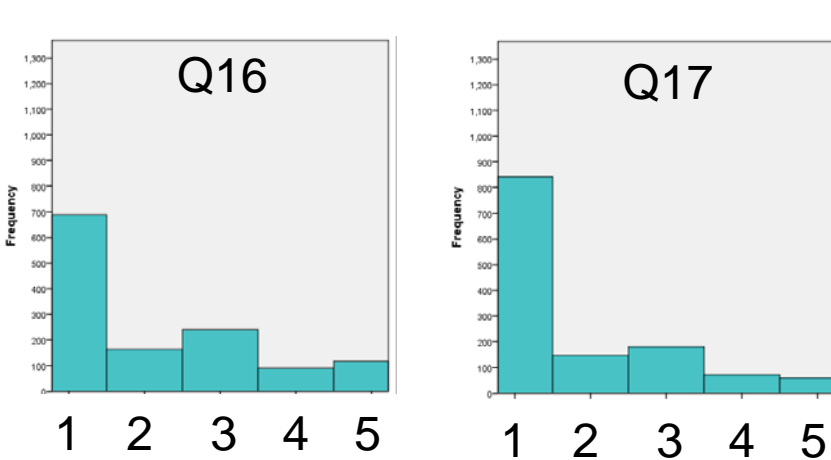
Hierarchical linear regression: Block 1, DFs; Block 2, stigma
Significance of R² change when adding stigma to model (F statistic): **p<0.001**
(all comparisons in this table were significant at this level)
When both internalized and experienced stigma are included in the model, they each independently improve the prediction model of all six PROs (p<0.001), but the interaction term does not further significantly improve the model, i.e., internalized and experienced stigma appear to have additive effects. (PRO: patient-reported outcome)

Results

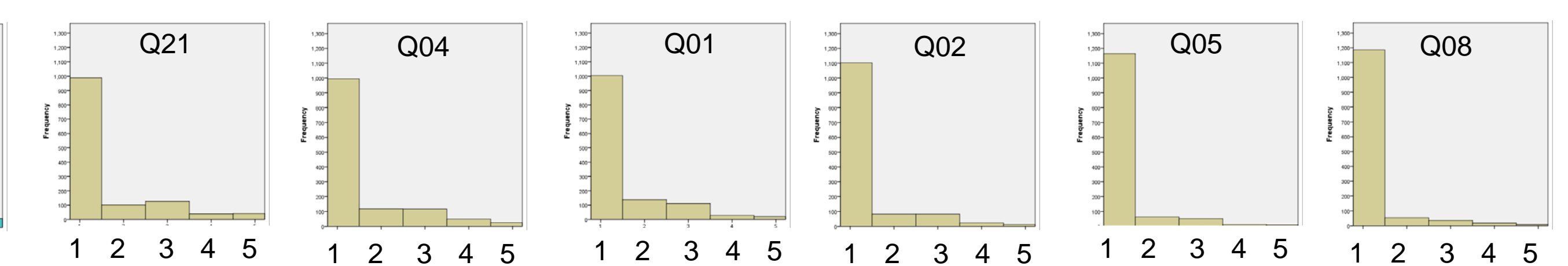
Sample Characteristics

	Baseline Sample (n = 1300)
Age, mean (SD), y	57.6 (10.9)
Male birth sex, n (%)	727 (55.9%)
Black race, n (%)	415 (31.9%)
Education above high school diploma/GED, n (%)	589 (45.3%)
Household income above \$40,000/y, n (%)	321 (24.7%)
Separated, divorced, or widowed, n (%)	362 (27.8%)
Employed (full- or part-time), n (%)	455 (35.0%)

Internalized Stigma



Experienced Stigma



Conclusions

- Black race, older age, and being employed were associated with lower rates of both internalized and experienced stigma.
- Both internalized and experienced stigma were associated with increased intensity of all 5 somatic/psychological patient-reported outcomes, and decreased quality of life, with additive effects between the two types of stigma.

Acknowledgments

This study was funded by a Patient-Centered Outcomes Research Institute (PCORI) Award (CER-1408-20660) to DM Evon.

References

- Cabrera, C.M., 2014. *Measurement of stigma and relationships between stigma, depression, and attachment style among people with HIV and people with hepatitis C* (Doctoral dissertation, Université d'Ottawa/University of Ottawa).
- Evon, D.M., Golin, C.E., Fried, M.W., and Keefe, F.J., 2013. Chronic hepatitis C and antiviral treatment regimens: where can psychology contribute? *Journal of consulting and clinical psychology*, 81(2), p.361.
- Zigmund, S., Ho, E.Y., Masuda, M., Ippolito, L. and LaBrecque, D.R., 2003. "They treated me like a leper": Stigmatization and the quality of life of patients with hepatitis C. *Journal of General Internal Medicine*, 18, pp.835-844.
- Golden, J., Conroy, R.M., O'Dwyer, A.M., Golden, D. and Hardouin, J.B., 2006. Illness-related stigma, mood and adjustment to illness in persons with hepatitis C. *Social science & medicine*, 63(12), pp.3188-3198.
- Treloar, C., Rance, J. and Backmund, M., 2013. Understanding barriers to hepatitis C virus care and stigmatization from a social perspective. *Clinical Infectious Diseases*, 57(suppl_2), pp.S51-S55.
- Evon, D.M., Golin, C.E., Stewart, P., Fried, M.W., Alston, S., Reeve, B., Lok, A.S., Sterling, R.K., Lim, J.K., Reau, N. and Sarkar, S., 2017. Patient engagement and study design of PROP UP: A multi-site patient-centered prospective observational study of patients undergoing hepatitis C treatment. *Contemporary clinical trials*, 57, pp.58-68.
- Molina, Y., Choi, S.W., Cella, D. and Rao, D., 2013. The stigma scale for chronic illnesses 8-item version (SSCI-8): development, validation and use across neurological conditions. *International journal of behavioral medicine*, 20(3), pp.450-460.