HealthPROMISE: Utilization of Patient Reported Outcomes to Measure Quality of Life in Inflammatory Bowel Disease

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Abstract

Background: Inflammatory Bowel Disease (IBD) is a chronic condition of the bowel affecting over 1.5 million people in the United States. The recurrent nature of IBD makes affected patients ideal candidates for electronic patient reported outcome (e-PRO) monitoring that centers on enhanced symptom tracking and improved communication with care teams.

Objective: The study aims to understand the impact of e-PRO utilization via a prescribed mobile application, HealthPROMISE, on improving patients' quality of life (QOL). Researchers investigated patients' use of e-PROs to determine whether physicians change treatment in response to new patient health information, and whether patients' quality of life changes over the course of the study.

Methods: In a pragmatic randomized trial at Mount Sinai Medical Center (MSMC), baseline e-PROs were measured using online questionnaires delivered through the app that assessed health literacy, disease severity, general health status, and demographic information. Patients using HealthPROMISE could update their e-PRO information and receive a disease summary and a graph trending IBD-specific QOL scores (Figure 1). Patients could also communicate over the HealthPROMISE app and discuss results with providers. Results of e-PRO data were then compared with those collected from paper-based instruments in another institution (University of Pittsburgh Medical Center, UPMC) for triangulation (Figure 2).

Results: There were 320 patients enrolled in the study. Of these, 162 were randomized to the intervention group (e-PROs), and 158 to the control group. Fatigue and tension were the two most important drivers of poor QOL in both MSMC and UPMC cohorts. Usage data showed that the majority of patients (~75%) continue to actively log into the HealthPROMISE app and update their e-PRO. Overall, QOL improved among HealthPROMISE patients over a mean follow-up of 6 months. At baseline, patients in the intervention arm reported a mean quality of life score of 30.3 ± 11.3 . The last available follow-up QOL scores showed improvement among patients using HealthPROMISE to 25.3 ± 11.3 (*P*<0.001) (Figure 2).

Conclusions: This is one of the first randomized controlled trials of app-based PRO measure in IBD patients. A significant improvement in QOL was observed. Longitudinal e-PRO collection in IBD patients is feasible with a high degree of adoption and engagement. IBD patients who participate in their own care (via PRO) and share in decision-making have appreciably improved outcomes when compared to patients who do not.

(*iproc 2017;3(1):e28*) doi: <u>10.2196/iproc.8452</u>

KEYWORDS

Quality of life; Self-Management; Inflammatory Bowel Disease; Remote Monitoring; Electronic Patient Reported Outcome

Figures



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Figure 1. Report showing utilization of PROs to measure quality of life and symptoms in IBD patients.

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Figure 2. Data on specific symptom drivers of poor quality of life scores (collected on HealthPROMISE platform) at MSMC (purple, n=320) compared with those collected on paper at UPMC (pink, n=685).





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Figure 3. Interim analysis showing improvement in symptom burdenamong intervention cohort at MSMC (P- value based on linear mixed effects model).



Multimedia Appendix 1

Full poster.

[PDF File (Adobe PDF File), 1MB-Multimedia Appendix 1]



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Edited by T Hale; this is a non-peer-reviewed article. Submitted 13.07.17; accepted 23.08.17; published 22.09.17. <u>Please cite as:</u> Atreja A, Otobo E, Chang H, Keefer L, Rogers J, Ullman T, Ramireddy K, Marion J, Deorocki A, Berde E, Zlatopolsky R, Kohli A, Choksi P, Itzkowitz S, Colombel JF, Sands B HealthPROMISE: Utilization of Patient Reported Outcomes to Measure Quality of Life in Inflammatory Bowel Disease iproc 2017;3(1):e28 URL: http://www.iproc.org/2017/1/e28/ doi: 10.2196/iproc.8452 PMID:

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