



Utilizing the Patient Reported Outcomes Measurement Information System (PROMIS®) to increase referral to ancillary support services for severely symptomatic patients with gynecologic cancer

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HIGHLIGHTS

- PROMIS ePRO assessments can identify severe cancer symptoms in gynecologic oncology.
- Patients find PROMIS ePROs easy to complete and helpful in addressing symptoms.
- PROMIS identification of severe symptoms increases referral to supportive services.
- Longitudinal studies must assess if ePRO scores improve with referral utilization.

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ABSTRACT

Objective. The Patient-Reported Outcomes Measurement Information System (PROMIS®) Network has developed a comprehensive repository of electronic patient reported outcomes measures (ePROs) of major symptom domains that have been validated in cancer patients. Their use for patients with gynecologic cancer has been understudied. Our objective was to establish feasibility and acceptability of PROMIS ePRO integration in a gynecologic oncology outpatient clinic and assess if it can help identify severely symptomatic patients and increase referral to supportive services.

Methods. English-speaking patients with a confirmed history of gynecologic cancer completed PROMIS ePROs on iPads in the waiting area of an outpatient gynecologic oncology clinic. Symptom scores were calculated for each respondent and grouped using documented severity thresholds. Response data was compared with clinicopathologic characteristics across symptom domains. Severely symptomatic patients were offered referral to ancillary services and asked to complete post-exposure surveys assessing acceptability of the ePRO.

Results. Of the 336 patients who completed ePROs, 35% had active disease and 19% had experienced at least one disease recurrence. Sixty-nine percent of the cohort demonstrated moderate to severe physical dysfunction (60%), pain (36%), fatigue (28%), anxiety (9%), depression (8%), and sexual dysfunction (32%). Thirty-nine (12%) severely symptomatic patients were referred to services such as psychiatry, palliative care, pain management, social work or integrative oncology care. Most survey respondents identified the ePROs as helpful (78%) and easy to complete (92%).

Conclusions. Outpatient PROMIS ePRO administration is feasible and acceptable to gynecologic oncology patients and can help identify severely symptomatic patients for referral to ancillary support services.

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1. Introduction

Because up to 20–66% of patients with cancer report high levels of distress, screening with Patient Reported Outcomes (PROs) surveys is now part of best practice guidelines in psychosocial cancer care and is endorsed by entities including the National Cancer Institute, American

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Cancer Society, the Food and Drug Administration, the Centers for Medicare and Medicaid Services and the National Institutes of Health (NIH) [1]. PROs are an important component of a growing body of health services research and clinical trials of patients with gynecologic cancers. However, a lack of consensus regarding domains of PRO assessment and limited validation of measures has made it difficult to compare and contrast early PRO studies.

In order to address this heterogeneity, the NIH funded the Patient-Reported Outcomes Measurement Information System (PROMIS) Network as a collaborative effort to advance and standardize the measurement of health-related quality of life (HRQL) in clinical practice, using state of the art psychometric and computer adaptive tests (CATs) [2]. The PROMIS Network has established a publicly available repository bank of standardized, accurate and efficient PRO measures of major self-reported health domains (e.g. pain, fatigue, emotional distress, physical function, social functioning) that are relevant across chronic illnesses including cancer [3]. These study instruments are available either on paper or electronically (ePROs) and have been validated in patients with cancer [2–6]. PROMIS assessments are ideal to assess HRQL as they are designed to have a low response burden for patients without sacrificing precision and quality for brevity [3].

At Montefiore Medical Center, we service a uniquely diverse population of patients in Bronx, New York. Of the 6700 clinic patients we see annually, 80% receive care paid for by Medicaid or Medicare. Eighty-five percent of our patients self-identify as Black race and/or Hispanic ethnicity and 30% live below the poverty line. Our unique patient population allows us to explore ePRO use in a racially and ethnically diverse community that has not been previously examined.

The objectives of this study were to assess implementation of selected PROMIS PROs to screen for severe cancer symptomatology in gynecologic oncology outpatients, to evaluate patient acceptability of administering PROMIS ePROs, and to identify if PROMIS can effectively increase referral of severely symptomatic patients to ancillary support services.

2. Methods

After Institutional Review Board approval, a prospective pilot study was performed over a six-month period between 2016 and 2017 in a gynecologic oncology outpatient clinic. Patients were considered eligible for inclusion if they were English-speaking and if they had a history of gynecologic cancer. After informed consent, patients were asked to complete PROMIS ePROs in the clinic waiting area prior to their scheduled appointment with their provider.

The ePRO assessment instrument was built using Assessment CenterSM and was composed of the following CATs: “PROMIS-Ca Bank v1.1 – Physical Function”, “PROMIS-Ca Bank v1.1 – Pain Interference”, “PROMIS-Ca Bank v1.0 – Fatigue”, “PROMIS-Ca Bank v1.0 – Depression”, “PROMIS-Ca Bank v1.0 – Anxiety” and the fixed item metric “PROMIS Female Sexual Function Profile v1.0”. These tests were designed to assess cancer symptoms across multiple domains including physical function, pain interference, fatigue, depression, anxiety and sexual function. The test was activated on iPads within the waiting area that would not allow the use of other software at the same time. Although a study coordinator was available to obtain informed consent from the patient and aid with iPad use, each patient was asked to fill out the survey by herself.

t-Scores were calculated in real time for each ePRO symptom domain using the HealthMeasures Scoring Service powered by Assessment CenterSM. Neither patients nor providers were aware of their symptom scores at the time of their clinic visit. After each clinic visit, patient scores were reviewed by study personnel and categorized by degree of severity using previously documented thresholds, with a mean score of 50 and an interval of each 10 points in either direction representing a standard deviation from the mean [7]. *t*-Scores corresponding with severe symptomatology for each domain are detailed

in Table 4. Patients with severe symptomatology in any domain were contacted by study personnel and were offered referral to ancillary support services via telephone within one week of ePRO completion. These supportive services included psychiatry, palliative care, social work, physical therapy, and Bronx Oncology Living Daily (BOLD) – an integrative cancer care program at Albert Einstein College of Medicine. Severely symptomatic patients completed surveys assessing satisfaction with the PROMIS ePRO at their next clinic visit (Supplementary Fig. 1).

Demographic and clinicopathologic characteristics of study participants were abstracted from the medical record. Charlson Comorbidity Index scores were calculated retrospectively using medical information obtained through chart review [8]. In order to reduce ascertainment bias, the study personnel abstracting information from the medical record were blinded to PROMIS ePRO results. These clinical variables were analyzed to assess association with severe symptomatology using bivariate analysis and simple logistic regression. Normality of continuous variables was visually assessed and if no substantial violations were noted, data was reported as means \pm standard deviations. Otherwise, they were reported as medians with interquartile ranges. Categorical data was presented as number of subjects with percentages. Continuous variables were assessed using two sample *t*-test or the Mann-Whitney *U* test, whereas categorical and dichotomous variables were examined using the chi-squared and Fisher's exact tests, as appropriate. A multivariable logistic regression model was fit to accurately characterize the association of individual covariates with severe symptomatology. Covariates were selected for inclusion if they were significant in bivariate analysis at $p < 0.25$. A backwards elimination approach was employed. Confounding was assessed for at each step of elimination (defined as a change in beta statistic for covariates by $>10\%$). First-order interactions were assessed for using product interaction terms (alpha for interaction = 0.05) and none were found. Regression diagnostics did not identify any potentially influential covariate patterns in the model. Odds ratios were reported with 95% confidence intervals. *p*-Values <0.05 were considered statistically significant. Data analysis was performed using Stata version 14.2 (College Station, TX: StataCorp LP).

3. Results

Of 370 patients who were offered study participation, a total of 336 patients completed ePRO surveys in the clinic waiting area (Table 1). Of the 34 patients who did not participate, 12 did not speak English fluently and the remaining 22 declined study enrollment. Patients each completed only one ePRO assessment and no patients participated more than once. Of these participants, 59 were severely symptomatic in at least one symptom domain. Mean age for the cohort was 65 years, and most patients (53%) were of non-white race. The majority of patients had uterine cancer (59%), followed by ovarian (23%), cervical (14%), and vaginal (1%) or vulvar cancer (3%). Although most patients had stage I disease (57%), many patients had stage III (21%) or stage IV (11%) cancers. Most patients were in disease remission (65%), but 19% had experienced at least one cancer recurrence and 35% were undergoing active cancer treatment at the time of ePRO completion.

Demographic and clinicopathologic data stratified by presence of severe symptomatology are presented in Table 2. The odds ratios reported refer to the odds of severe symptomatology for each covariate calculated using simple logistic regression. The median Charlson Comorbidity Index for the group was 6, however this was not significantly associated with severe symptomatology in any symptom domain. Patient age, race, ethnicity and disease stage were also not significantly associated with severe cancer symptoms in simple logistic regression. Patients with ovarian cancer were more likely to have severe symptoms relative to uterine cancer (OR 3.32; 95% CI 1.73–6.39) and those with active disease were more symptomatic than those in remission (OR 2.22; 95% CI 1.26–3.93). Disease recurrence was also significantly associated with severe symptomatology (OR 1.93; 95% CI 1.01–3.68) relative to initial

Table 1
Demographic and clinicopathologic data for patients who completed PROMIS ePROs (N = 336)^a.

Characteristics	N (%)
Age (years)	65 ± 12
Charlson Comorbidity Index	6 (4,8)
Race	
– White	157 (47)
– Black	128 (38)
– Other	51 (15)
Ethnicity	
– Non-Hispanic	221 (66)
– Hispanic	96 (29)
– Other	19 (5)
Stage	
– Stage I	191 (57)
– Stage II	36 (11)
– Stage III	72 (21)
– Stage IV	37 (11)
Disease site	
– Uterine	199 (59)
– Ovarian/fallopian/PPC	76 (23)
– Cervical/vaginal/vulvar	61 (18)
No evidence of disease	218 (65)
Active disease	118 (35)
– Post-operative	31 (9)
– On chemotherapy	74 (22)
– On radiation	13 (4)
Recurrent disease	65 (19)

^a Data with plus-minus values represent means ± standard deviation, otherwise reported as median (interquartile range). Categorical data are presented as N (%) associated with odds ratios and 95% confidence intervals.

cancer diagnosis. After adjustment, multivariable logistic regression analysis revealed that only primary disease site and presence of active disease were significantly associated with presence of severe symptomatology (Table 3).

Table 2
Demographic and clinicopathologic data for patients who completed PROMIS ePROs stratified by severe symptomatology (N = 336)^a.

Characteristics	Not severely symptomatic (N = 277)	Severely symptomatic (N = 59)	OR	95% CI	p value
Age (years)	65 ± 12	62 ± 13			0.08
Charlson Comorbidity Index	5 (4,8)	6 (3,8)			0.28
Race					
– White	130 (47)	27 (46)	1.00	Ref	0.92
– Black	106 (38)	22 (37)	1.00	0.54–1.86	
– Other	41 (15)	10 (17)	1.17	0.52–2.63	
Ethnicity					
– Non-Hispanic	183 (66)	38 (64)	1.00	Ref	0.26
– Hispanic	76 (27)	20 (34)	1.27	0.69–2.32	
– Other	18 (7)	1 (1.7)	0.27	0.03–2.07	
Stage					
– Stage I	164 (59)	27 (46)	1.00	Ref	0.21
– Stage II	28 (10)	8 (14)	1.74	0.72–4.20	
– Stage III	58 (21)	14 (24)	1.47	0.72–2.99	
– Stage IV	27 (10)	10 (17)	2.25	0.98–5.17	
Disease site					
– Uterine	176 (64)	23 (39)	1.00	Ref	<0.01
– Ovarian/fallopian/PPC	53 (19)	23 (39)	3.32	1.73–6.39	
– Cervical/vaginal/vulvar	48 (17)	13 (22)	2.07	0.98–4.39	
No evidence of disease	189 (68)	29 (49)	1.00	Ref	<0.01
Active disease	88 (32)	30 (51)	2.22	1.26–3.93	
– Post-operative	22 (8)	9 (15)	2.67	1.12–6.35	0.03
– On chemotherapy	55 (20)	19 (32)	2.25	1.17–4.32	
– On radiation	11 (4)	2 (3)	1.18	0.25–5.62	
Recurrent disease	48 (17)	17 (29)	1.93	1.01–3.68	0.04

^a Data with plus-minus values represent means ± standard deviation, otherwise reported as median (interquartile range). Categorical data are presented as N (%) associated with odds ratios and 95% confidence intervals. Odds ratios refer to the odds of being severely symptomatic for each covariate using simple logistic regression.

Table 3
Multivariate logistic regression model examining association of clinical and demographic data with severe symptomatology adjusting for covariates (N = 336).

Characteristics	Odds ratio ^a	95% CI
Disease site		
– Uterine	1.00	Ref
– Ovarian/fallopian/PPC	3.13	1.61–6.07
– Cervical/vaginal/vulvar	1.97	0.92–4.21
Disease status		
– No evidence of disease	1.00	Ref
– Active disease	2.06	1.15–3.68

^a These values reflect adjusted odds ratios and all variables listed are covariates retained in the final model after adjustment.

Fifty-nine patients were identified who had severely symptomatic *t*-scores in at least one symptom domain. The most frequently identified symptoms were physical dysfunction, pain interference and fatigue (Table 4). Although only 3 participants scored as being severely symptomatic in terms of sexual interest, many participants had moderately severe dysfunction with sexual lubrication (32%), global sexual satisfaction (20%), interest in sexual activity (1%) and vaginal discomfort (7%).

Of the 59 severely symptomatic patients identified during the course of the study, 36 (61%) completed follow-up satisfaction surveys at their next clinic visit. Median time from ePRO completion to follow-up satisfaction survey completion was 21 days (IQR 12–60 days). Seventy-eight percent of respondents identified the ePRO instrument as helpful or very helpful in addressing their symptoms and 92% reported that the questions were easy or very easy to understand. The ePRO took a median of 10 min (range 5–20 min) for respondents to complete and 72% of respondents said they would be likely or very likely to complete a symptom assessment in the future. Illustrative free-text responses from survey respondents are listed in Supplementary Fig. 2. Comments were overall positive and indicated generalized acceptability of the instrument.

All 59 severely symptomatic patients were contacted within 1 week of completion of the ePRO instrument and offered referral to ancillary supportive care services. Twenty of these patients (34%) declined referral whereas 39 patients (66%) were referred to services such as psychiatry (n = 10), palliative care (n = 28), social work (n = 2), physical therapy (n = 10), and BOLD (n = 17) (Fig. 1). None of these referrals to supportive care were made by their treating gynecologic oncologist during their clinic encounter. A total of 67 referrals were made (1.7 referrals per patient) through PROMIS identification of severe symptoms.

4. Discussion/significance

Our study demonstrated that administration of PROMIS ePROs in a gynecologic oncology outpatient clinic was feasible and that most patients found PROMIS ePROs helpful and easy to complete. PROMIS ePRO administration in our population was able to successfully identify severely symptomatic patients for referral to supportive cancer care. This is particularly important given that despite the severity of their symptoms, these patients were not referred to ancillary services by their providers.

Without performing this pilot study in other patient populations, we have no way of ensuring the external validity of our results. However, our patient cohort includes broad representation of women of multiple ethnicities, different cancer types, stages of disease and treatment status. We therefore believe that this study has a high likelihood of representing patient populations found in the average gynecologic oncology clinic. The high prevalence of moderate to severe symptomatology in our patient cohort is comparable to other studies assessing HRQL in patients with gynecologic cancer [9–11]. Gynecologic oncology patients experience a high burden of symptoms regardless of their stage or cancer type [12]. Gynecologic cancers have the potential to negatively impact physical, mental/psychological and social functioning and may

Table 4
PROMIS ePRO symptoms scores in each symptom domain grouped by severity (N=336).

Domain [§]	N (%)	Mean ± SD*	T-Scores [†]			
			Normal	Mild	Moderate	Severe
Physical Function	332 (98.8)	44.5 ± 11.9	> 55	46–54	31–45	≤ 30
			85 (26)	48 (14)	163 (49)	36 (11)
Pain Interference	329 (97.9)	54.5 ± 11.1	< 50	50–59	60–69	≥ 70
			110 (33)	100 (30)	95 (29)	24 (7)
Fatigue	329 (97.9)	53.4 ± 11.5	< 50	50–59	60–69	≥ 70
			119 (36)	119 (36)	65 (20)	26 (8)
Depression	329 (97.9)	50.0 ± 10.8	< 55	55–64	65–74	≥ 75
			221 (67)	83 (25)	20 (6)	5 (2)
Anxiety	328 (97.6)	52.6 ± 10.3	< 55	55–64	65–74	≥ 75
			199 (61)	100 (31)	19 (6)	10 (3)
Lubrication	127 (37.8)	55.1 (50.6, 63.3)	< 50	50–59	60–69	≥ 70
			25 (20)	62 (49)	40 (32)	0
Global Sexual Satisfaction	84 (25.0)	48.2 (44.4, 55.7)	< 50	50–59	60–69	≥ 70
			45 (54)	22 (26)	17 (20)	0
Interest in Sexual Activity	323 (96.1)	39.8 (33.4, 46.7)	< 50	50–59	60–69	≥ 70
			269 (83)	47 (15)	4 (1)	3 (1)
Vaginal Discomfort	89 (26.5)	46.8 (41.0, 52.5)	< 50	50–59	60–69	≥ 70
			57 (64)	26 (29)	6 (7)	0

[§] Symptomatic domains assessed using the following CAT ePRO tests and fixed item metrics: PROMIS Cancer v 1.1 – Physical Function, Pain Interference/PROMIS Cancer v 1.0 – Fatigue, Depression, Anxiety/PROMIS Female Sexual Function Profile v 1.0, Female Lubrication, Global Satisfaction with Sexual Life, Interest in Sexual Activity, Vaginal Discomfort.

* Sexual function data reported as median (interquartile range).

[†] Grey subheadings refer to t-score groupings; white row data reported as N (%).

diminish personal perception of femininity, self-esteem and body image [13]. The scientific basis for selection of the domains assessed in this study is that they represent functional domains that are commonly affected by gynecologic malignancy. We detected a low prevalence of severe sexual dysfunction in our study compared with other studies in gynecologic oncology patients using other assessment tools [14–16]. Multiple participants mentioned they felt uncomfortable answering questions about sexual health which may account for lower reporting. However, many of our patients experienced moderate dysfunction in at least one sexual dysfunction domain, indicating that the instrument

is likely still helpful in screening for sexual health in our patient population.

It is also not surprising that participants in our study had positive opinions regarding ePRO administration in our clinic. Patients often feel dissatisfied with the amount of time spent discussing their symptoms with their medical teams and many clinicians lack the time and confidence necessary to address these important issues [17]. Our patients felt that the ePRO demonstrated that their providers cared about their symptoms. Study participants also identified the ePRO as easy and quick to complete, taking a median of only 10 min. PROMIS integrates item response theory (IRT), a psychometric method for statistical calibration of scores based on each individual's response to a question. The CAT software uses these scores to determine appropriate and useful follow-up questions, thus maximizing information provided while minimizing burden on patient respondents. ePROs administered in other studies to assess patient HRQL in the waiting room have demonstrated compliance rates of up to 75% [18]. It should be noted that the metric used to assess sexual function in this study (PROMIS Female Sexual Function Profile v1.0) is not a CAT but rather a fixed-item metric.

Perhaps the most important finding of our study is that ePROs administration followed by provider telephone follow-up not only resulted in multiple referrals per symptomatic patient, but that none of these patients were referred to ancillary services by their own providers. It is unknown why providers did not make these referrals and further research is needed to evaluate if the low referral rate by providers was associated with inadequate clinical time or diagnostic expertise. Patients may feel uncomfortable bringing up sensitive topics without prompting, especially if their provider appears rushed or has a different approach to directing the patient interview.

Our study carries many important limitations. As this is a cross-sectional study, examining patient symptoms at one snapshot in time, we have no longitudinal information about our cohort. We do not have follow-up data confirming that patients made it successfully to their referral appointments, what barriers they faced along the way, or whether or not their symptom scores improved after referral. We also do not have data regarding whether study participants discussed their referrals subsequently with their physicians or whether clinicians did

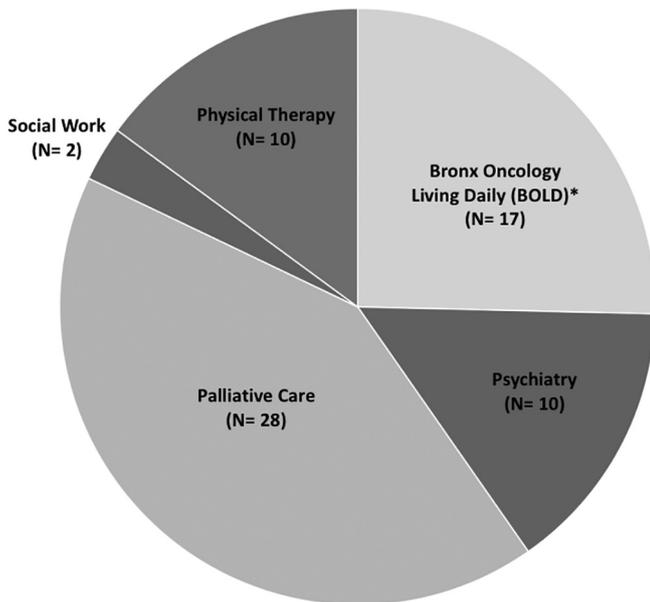


Fig. 1. Ancillary services to which patients were referred through PROMIS ePRO identification of severe cancer symptomatology (N = 39, total referrals = 67) *BOLD = Bronx Oncology Living Daily (an integrative cancer care program at Albert Einstein College of Medicine).

not feel referral was necessary. Although our study included many Hispanic patients and patients of non-white race, our ePRO instrument was only available in English and therefore, we are unable to determine if it would be broadly applicable to non-English speaking patients with gynecologic cancer.

Our study is limited in that we only have follow-up survey response data from severely symptomatic patients in the cohort. Ideally, we would have been able to sample the entire study population, but this was not feasible in this pilot study. We selected severely symptomatic patients as a purposeful subpopulation to administer follow-up surveys because this is the group of women for whom the ePRO instrument was designed to identify. Future studies will include global assessment of acceptability in all gynecologic oncology patients.

5. Conclusions

Our study demonstrates that administration of PROMIS ePROs in a gynecologic oncology outpatient clinic can feasibly identify severely symptomatic patients for referral to ancillary support services, above and beyond provider identification of symptoms during office visits. These instruments are easy for patients to complete and are generally acceptable to most patients. Further mixed-methods studies and longitudinal assessments are necessary to determine what barriers patients face in the referral process, if PROMIS ePRO scores improve after successful referral, and if implementation of these instruments is cost-effective.

Supplementary data to this article can be found online at <https://doi.org/10.1016/j.ygyno.2018.10.042>.

Conflict of interest statement

The authors of this study have no relevant conflicts of interest to disclose.

Author contributions

Dr. Gressel is the primary author on the manuscript. He conceived of the study design and along with the co-authors, executed the study, analyzed the data and wrote the final manuscript.

Dr. Dioun and Richley helped with the data analysis and contributed to key portions of the final manuscript.

Drs. Lounsbury and Rapkin are experts in psychometric theory and systems science and served as study consultants in this respect. They edited and made important contributions to the final manuscript.

Drs. Isani, Nevadunsky and Kuo helped in executing the study and collecting the study data. They edited and made important contributions to the final manuscript.

Dr. Novetsky is the senior author on the manuscript. He oversaw all portions of the study design and implementation and made key contributions to the final manuscript.

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