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# Perceptions of patient-centered care among veterans with gastroesophageal reflux disease on proton pump inhibitor therapy

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## Abstract

The aim of this study was to explore perceptions of patient-centered care (PCC) among Veterans with gastroesophageal reflux disease (GERD) on proton pump inhibitor (PPI) therapy using patient-reported outcome (PRO) measures. We used three validated surveys to measure PCC concepts in a national sample of Veterans with GERD on PPI therapy. The Combined Outcome Measure for Risk Communication and Treatment Decision Making Effectiveness (COMRADE) measures patient experiences with risk communication and decision-making. The Patient Activation Measure (PAM) evaluates confidence and knowledge needed for self-management. The Patient Assessment of Care for Chronic Conditions (PACIC) assesses views of chronic care received. We used descriptive statistics to describe patient characteristics and PCC outcomes. Respondents (n=444) were mostly male (95.1%) with a mean age of 67.7 years. The mean COMRADE score measuring patient experiences with risk communication was 55.3 (SD=19.0). The mean PAM score was 56.1 (SD=19.2); 47.8% of respondents were considered disengaged patients lacking confidence and knowledge for self-management. The mean PACIC summary score was 3.03 (SD=1.2), with highest scores in the Delivery System Design/Decision Support (3.38, SD=1.2) subscale, and lowest scores in the Follow-up/Coordination subscale (2.58, SD=1.3). Veterans with GERD reported that care was well-organized and supportive in enhancing decision-making. Potential gaps in patient experiences may exist in delivering follow-up care, enhancing patient activation, and informing patients about risks of available GERD treatments. This is the first study to evaluate patient perceptions of PCC in a national sample of Veterans with GERD on PPI therapy. Findings can inform further investigation and development of targeted interventions to enhance the experience of PCC for individuals with GERD.

## Introduction

Gastroesophageal reflux disease (GERD) is a common chronic condition that affects up to 28% of the North American population.[1] Among all digestive diseases in the United States, GERD accounts for the highest direct health care costs and represents the leading diagnosis in the outpatient care setting.[2-3] The disease is characterized by a broad range of troublesome esophageal symptoms, including heartburn, acid regurgitation, reflux esophagitis, stricture, Barrett's esophagus, and adenocarcinoma, as well as several extraesophageal complications.[4-5] In light of the complex nature and increasing prevalence, there is

considerable variability around the impact of GERD symptoms on patients.[6-8]

This variability extends into the delivery of chronic care for individuals with GERD, where substantial differences and gaps exist in establishing initial diagnoses, coordinating follow-up care, and measuring quality of care.[9-11] Furthermore, a central challenge in caring for individuals with GERD stems from treatment management with proton pump inhibitor (PPI) therapy. Although widely regarded as an effective treatment strategy, numerous studies have highlighted trends of inappropriate use and suboptimal dosing of PPI therapy.[12-15] These patterns are problematic given the rising costs and

documented health risks associated with long-term PPI use,[16-19] and given evidence that a significant proportion of PPI users continues to experience breakthrough GERD symptoms and reports lower levels of satisfaction with treatment.[9, 20]

To enhance care for patients with GERD, a patient-centric model may be especially beneficial. Patient-centered care (PCC) calls for the redesign of health services to tailor care around patient needs and preferences, enhance quality of care, and integrate care processes.[21] The model may be well-suited for GERD care because of its individualized approach to address complex, chronic diseases,[22-23] its emphasis on efficient and evidence-based care, and its focus on patient engagement.[24] In light of increased media coverage around the risks of PPI treatment and subsequently heightened patient concerns,[25] patient-centered approaches that are responsive to individual needs and preferences may be particularly helpful.

PCC is tied closely to patients' experience of care. Cornerstones of PCC—including understanding the patient journey and providing personalized care—are aligned with current definitions of the patient experience.[26] These are increasingly important to consider given the inclusion of patient experience as an indicator of quality and performance within health care organizations.[27] To our knowledge, no published studies have focused on patient experiences related to GERD, but these are needed to understand and improve care around patients' unique needs. Measuring patient experiences can be challenging; however, prior literature suggests that successful approaches are centered on what matters most to patients.[28] Thus, PCC outcomes that focus on patient views of their own care may offer a useful lens to study patient experiences.

In the United States, the Veterans Affairs (VA) Health Care System is one of many health care organizations to adopt PCC.[29] An essential component of PCC implementation is obtaining patient-level evaluations of care to better understand patient experiences and outcomes.[30] Deriving patient-reported insights, moreover, is an important prerequisite for developing strategies that enhance care in a way that aligns with the needs of patients with GERD.[31] Although patient-reported outcome (PRO) measures have been used to assess clinical symptoms among patients with GERD,[32] few studies demonstrate the use of PRO measures to describe PCC outcomes, including experiences and perspectives around chronic care delivery and organization, patient activation, decision-making, and self-management. In particular, limited data exist that describe PCC outcomes among Veteran patients with GERD on PPI therapy, yet this information is needed to enhance the quality of PCC for an increasingly large and diverse population affected by GERD. Our aim

was to explore perceptions of PCC among Veteran patients with GERD on PPI therapy using PRO measures.

## Methods

### Study Design and Respondents
The Center for Evaluation of Practices and Experiences of Patient Centered Care (CEPEP) is a VA funded project (PEC-13-002, PI: LaVela) to evaluate a range of PCC outcomes across the VA Health Care System. As part of this project, we conducted a cross-sectional mailed survey of Veterans with GERD who received care from eight nationally representative VA health care facilities across the northeastern/mid-Atlantic, southeastern, southwestern and western regions. During February and March 2013, we mailed a cover letter describing the purpose of the study, a survey, and a pre-paid VA business reply envelope to eligible respondents. We performed a follow-up mailing of the survey in mid-2013 to Veterans who had not responded to the original mailing. We used VA administrative databases to identify eligible respondents and used stratified random sampling and Dillman's sample size selection equation[33] to ensure adequate power and generalizability of our findings to the broader Veteran population.

Inclusion criteria for this study were Veteran patients with a clinical outpatient diagnosis of GERD (ICD-9 codes: 530.81 and 530.11) who were prescribed PPI therapy within 30 days following GERD diagnosis and who had received health care from a VA facility during the prior 6 months. PPI doses (standard or high dose prescriptions) were calculated as the ratio of quantity of medication/day's supply of medication at initial prescription. Long-term PPI use was defined as six months or more of therapy. We used VA administrative databases to extract GERD and other chronic condition data, as well as health care utilization information for a one-year period (October 1, 2012 – September 30, 2013) for all respondents.

This study was conducted as part of a larger quality improvement effort by VA health care facilities to evaluate PCC using methods that capture patient perspectives.

### Survey Measures and Data Sources
The survey included questions on patient demographics (age, sex, race, ethnicity, education), recent hospital or doctor visits, and three validated PRO instruments that assessed PCC outcome measures. These measures included the (1) Combined Outcome Measure for Risk Communication and Treatment Decision Making Effectiveness (COMRADE), the (2) Patient Activation Measure (PAM) instrument, and the (3) Patient Assessment of Care for Chronic Conditions (PACIC). Each measure is intended to capture key elements of the patient experience,[28] including patient-provider

communication, decision making, patient involvement in care, and coordination and continuity of care.

COMRADE. The COMRADE is a 20-item scale that assesses levels of patient perception of effective risk communication and confidence in shared decision-making as it relates to medical treatment. The instrument subscales include risk communication and decision-making effectiveness and represent distinct shared decision-making constructs.[34] The risk communication subscale addresses the information exchange between patients and providers around the potential risks and benefits of treatment. The decision-making effectiveness subscale is focused on the outcome of the information exchange and decision-making processes.[35] Items are evaluated on a 5-point Likert scale (where 1=strongly disagree and 5=strongly agree). Overall COMRADE scores are defined across a range of 0 to 100, where higher scores indicate better communication and outcomes, as well as more informed and effective decision-making.[35]

PAM. The short-form version of the PAM is a 13-item instrument designed to measure the degree to which patients are engaged in their health care and possess the knowledge, skills and confidence needed for self-management. The instrument helps generate a patient activation score that places respondents into one of four categories (levels 1-4), each representing an increasingly higher level of activation.[36] Using a Likert scale, respondents are asked to evaluate their level of agreement with statements reflecting the 4-step developmental process of patient activation. Activation stages include Stage 1: believing the patient role is important; Stage 2: having the confidence, knowledge and skills needed to take action; Stage 3: taking action to maintain self-management; Stage 4: sustaining the course under stress. PAM scores range from 1 to 100, where higher scores indicate better skills, knowledge and behaviors necessary for self-management as well as greater patient activation along the four stages. Raw scores are converted into an overall patient activation score and subsequently interpreted using a table developed by Hibbard and colleagues.[36-37]

PACIC. The PACIC is a 20-item instrument that assesses patient perceptions of the chronic care received. The instrument is organized into five subscales that address elements of PCC as perceived by patients with chronic illness; these subscales include Patient Activation, Delivery System Design/Decision Support, Goal Setting, Problem Solving/Contextual Counseling, and Follow-up/Coordination.[38] Respondents are asked to evaluate chronic care received over the last six months. Individual PACIC items are scored on a 5-point Likert scale, where 1=no/never and 5=yes/always. The overall PACIC summary score is the average of all 20 items. Subscales are scored by averaging the values of responses corresponding

to each subscale. Higher scores indicate higher or more favorable perceptions of chronic care received in the last six months.[39]

***Statistical Analysis***
All analyses were conducted using SAS software version 9.3 (SAS Institute Inc., Cary, NC). We used descriptive statistics to characterize the overall sample and assess PCC outcomes. We determined overall summary scores and subscale scores for each survey measure among Veterans diagnosed with GERD and prescribed PPI therapy.

## Results

The surveys were mailed to 1,777 Veteran patients with a GERD diagnosis who were prescribed PPIs. Of these, a total of 41 surveys were undeliverable, 11 patients had died, and 2 surveys were returned unopened or indicated as 'not applicable,' leaving 1,723 Veterans. The survey was completed by 444 Veteran patients (25.8% response rate) who had complete survey data for the COMRADE, PAM and PACIC instruments; these Veterans were included in the final analyses.

The average age of our sample was 67.7 years (SD=11.3) and respondents were predominantly male (95.1%). A majority of respondents (70.4%) self-reported their race/ethnicity as non-Hispanic white. Approximately 23.3% reported completion of a college degree or higher level of education. Nearly 67.0% of respondents reported having three or more chronic conditions. Almost all respondents (99.8%) reported having one or more recent outpatient visits. Approximately 81.3% of respondents reported that they had seen a VA doctor or visited a VA health care facility in the six-month period preceding receipt of the survey (August 2012-February 2013). A majority of respondents (87.2%) reported long-term PPI use; and 53.1% had high total daily dose initial PPI prescriptions. Sample characteristics are presented in Table 1.

The mean COMRADE score measuring patient experiences with risk communication was 55.3 (SD=19.0); the mean score measuring patient experiences with decision-making was 61.0 (SD=17.3). Higher scores were generally achieved in the decision-making effectiveness subscale compared with the risk communication subscale. Within the decision-making subscale, highest scores (indicating more effective shared decision-making) were noted in items that asked about the extent to which respondents felt they could easily discuss their medical condition with their doctor (3.90, SD=1.24) and their level of confidence in treatment decisions that were made with their doctor (3.72, SD=1.27). Within the risk communication subscale, highest scores (denoting more effective information exchanges between patients and providers around treatment risks and benefits) were found

**Table 1. Sample characteristics**

| Characteristic | Mean (SD) or Percent |
|---|---|
| **Age (n = 438)** | |
| mean (range, standard deviation) | 67.74 (31 – 93, SD=11.33) |
| **Sex (n = 444)** | |
| Male | 95.05 |
| Female | 4.95 |
| **Race (n = 439)** | |
| White | 70.39 |
| Black | 20.50 |
| Hispanic | 7.97 |
| Asian | 0.68 |
| Hawaiian / Pacific Islander | 0.46 |
| **Ethnicity (n = 430)** | |
| Hispanic | 8.14 |
| Non-Hispanic | 91.86 |
| **Education (n = 442)** | |
| Some or no college | 76.70 |
| College Graduate | 23.30 |
| **Average distance from VA (miles) (n = 444)** | |
| mean (range, standard deviation) | 30.66 (0.12 – 314, SD=33.7) |
| **Recent doctor or hospital visits in last 6 months (n = 444)** | |
| Yes, VA | 81.31 |
| Yes, non-VA | 24.10 |
| No | 4.05 |
| **Characteristic** | **Mean (SD) or Percent** |
| **Number of chronic conditions (n = 444)** | |
| 1-2 | 33.11 |
| 3 or more | 66.89 |
| **Number of inpatient discharges (n = 444)** | |
| mean (range, standard deviation) | 0.22 (0 – 5, SD=0.67) |
| **Length of stay [a] (n = 57)** | |
| Mean (range, standard deviation) | 9.14 (1 – 48, SD=10.59) |
| **Number of 24-hour observation stays (n = 444)** | |
| mean (range, standard deviation) | 0.04 (0 – 4, SD=0.29) |
| **Emergency room visits (n = 444)** | |
| mean (range, standard deviation) | 0.60 (0 – 12, SD=1.51) |
| **Outpatient visits (n = 444)** | |
| mean (range, standard deviation) | 24.0 (0 – 234, SD=22.27) |

[a] *Among those who had an inpatient discharge.*

specifically in items that addressed the extent to which patients felt they knew the advantages (3.84, SD=1.19) and disadvantages (3.88, SD=1.17) associated with treatment. Lowest scores were within the risk communication subscale. These items asked respondents to comment on the degree to which they felt their doctor had given them a chance to decide which treatment was best for themselves (3.35, SD=1.39), and the degree to which they felt their doctor had given them enough information about the various treatment options available (3.43, SD=1.36). Item responses for the COMRADE are presented in Table 2.

The mean overall PAM score was 56.1 (SD=19.2). Approximately 47.8% of respondents were in the first and second stages of activation, indicating disengaged patients lacking confidence and knowledge to manage their health. Specifically, 28.4% were categorized in the first stage, and 19.4% in the second. We found that 52.3% of respondents were in the third and fourth stages of activation, representing activated, goal-oriented patients who maintain self-management, and effectively engage with health care teams. Approximately 27.8% of respondents were classified in the third stage of patient activation, and 24.8% in the fourth stage. Highest scores were achieved in items that asked respondents about the extent to which they felt

**Table 2. COMRADE Item Scores**

| COMRADE Item | Mean (range) Standard Deviation (n=444) |
|---|---|
| 1. The doctor made me aware of the different treatments available | 3.45 (1.0 – 5.0) 1.31 |
| 2. The doctor gave me the chance to express my opinions about the different treatments available | 3.44 (1.0 – 5.0)1.34 |
| 3. The doctor gave me the chance to ask for as much information as I needed about the different treatment choices available | 3.46 (1.0 – 5.0) 1.38 |
| 4. The doctor gave me enough information about the treatment choices available | 3.43 (1.0 – 5.0) 1.36 |
| 5. The doctor gave enough explanation of the information about the treatment choices | 3.44 (1.0 – 5.0) 1.33 |
| 6. The information given to me was easy to understand | 3.58 (1.0 – 5.0) 1.27 |
| 7. I know the advantages of treatment or not having treatment | 3.84 (1.0 – 5.0) 1.19 |
| 8. I know the disadvantages of treatment or not having treatment | 3.88 (1.0 – 5.0) 1.17 |
| 9. The doctor gave me a chance to decide which treatment I thought was best for me | 3.35 (1.0 – 5.0) 1.39 |
| 10. The doctor gave me a chance to be involved in the decisions during the consultation | 3.47 (1.0 – 5.0) 1.40 |
| 11. Overall, I am satisfied with the information I was given | 3.61 (1.0 – 5.0) 1.27 |
| 12. My doctor and I agreed about which treatment (or no treatment) was best for me | 3.62 (1.0 – 5.0) 1.33 |
| 13. I can easily discuss my condition again with my doctor | 3.90 (1.0 – 5.0) 1.24 |
| 14. I am satisfied with the way in which the decision was made in the consultation | 3.71 (1.0 – 5.0) 1.29 |
| 15. I am sure that the decision made was the right one for me personally | 3.71 (1.0 – 5.0) 1.27 |
| 16. I am satisfied that I am adequately informed about the issues important to the decision | 3.70 (1.0 – 5.0) 1.24 |
| 17. It's clear which choice is best for me | 3.64 (1.0 – 5.0) 1.28 |
| 18. I'm aware of the treatment choices I have | 3.63 (1.0 – 5.0) 1.29 |
| 19. I feel an informed choice has been made | 3.66 (1.0 – 5.0) 1.27 |
| 20. The decision shows what is most important for me | 3.70 (1.0 – 5.0) 1.25 |

that they are the person who is responsible for managing their own health condition (3.34, SD=0.64), and the extent to which they believed that taking an active role in their own health care was the most important factor in determining their health and ability to function (3.42, SD=0.56). Lowest scores were noted in items that focused on respondents' confidence in determining solutions when new problems occur with their health (2.60, SD=0.67), and their confidence in maintaining lifestyle changes, including diet and exercise, during times of stress (2.78, SD=0.69). Item responses for the PAM are shown in Table 3.

The mean PACIC summary score was 3.03 (SD=1.2). Respondents achieved highest scores in the Delivery System Design/Decision Support (3.38, SD=1.2) and Patient Activation subscales (3.26, SD=1.3). Within these subscales, items with the highest scores included those that asked respondents about the extent to which they were encouraged to talk about any problems with their medicines or their effects (3.45, SD=1.36); the extent to which they were satisfied that their chronic care was well-organized (3.72, SD=1.19); and the extent to which respondents were shown how steps they took to take care of their health influenced their chronic condition (3.32, SD=1.34). Lowest scores were in the Follow-up/Coordination (2.58, SD=1.3) and Goal Setting/Tailoring subscales (2.98, SD=1.3). Within these subscales, lowest scores were specifically noted in items

### Table 3. PAM Item Scores

| PAM Item | Mean (range) Standard Deviation (n=444) |
|---|---|
| 1. When all is said and done, I am the person who is responsible for taking care of my health (n=443) | 3.34 (1.0 – 5.0) 0.64 |
| 2. Taking an active role in my own health care is the most important thing that affects my health (n=440) | 3.42 (1.0 – 5.0) 0.56 |
| 3. I am confident I can help prevent or reduce problems associated with my health (n=439) | 3.13 (1.0 – 5.0) 0.63 |
| 4. I know what each of my prescribed medications do (n=441) | 3.10 (1.0 – 5.0) 0.66 |
| 5. I am confident that I can tell whether I need to go to the doctor or whether I can take care of a health problem myself (n=441) | 3.06 (1.0 – 5.0) 0.66 |
| 6. I am confident that I can tell a doctor concerns I have even when he or she does not ask (n=440) | 3.18 (1.0 – 5.0) 0.65 |
| 7. I am confident that I can follow through on medical treatments I may need to do at home (n=441) | 3.25 (1.0 – 5.0) 0.59 |
| 8. I understand my health problems and what causes them (n=439) | 3.01 (1.0 – 5.0) 0.69 |
| 9. I know what treatments are available for my health problems (n=441) | 2.87 (1.0 – 5.0) 0.70 |
| 10. I have been able to maintain (keep up with) lifestyle changes, like eating right or exercising (n=443) | 2.87 (1.0 – 5.0) 0.71 |
| 11. I know how to prevent problems with my health (n=433) | 2.92 (1.0 – 5.0) 0.62 |
| 12. I am confident I can figure out solutions when new problems arise with my health (n=438) | 2.60 (1.0 – 5.0) 0.67 |
| 13. I am confident that I can maintain lifestyle changes, like eating right and exercising, even during times of stress (n=443) | 2.78 (1.0 – 5.0) 0.69 |

that addressed the extent to which respondents were asked how their visits with other doctors were going (2.60, SD=1.53); the extent to which respondents were encouraged to attend programs in their community that could help them (2.24, SD=1.44); and the extent to which respondents were encouraged to go to specific groups or classes to help them better cope with their chronic condition (2.78, SD=1.54). Item responses for the PACIC are included in Table 4.

## Discussion

To our knowledge, this is the first study to evaluate patient perceptions of PCC in a national sample of Veterans with GERD on PPI therapy. Using three validated PRO measures to assess PCC, we learned that perceptions of care among patients with GERD on PPI therapies were generally high and favorable overall. Patients reported that care was well-organized, supportive in enhancing their decision-making, and effective in improving their understanding of care. However, our findings also reveal several potential areas of improvement that can be

**Table 4. PACIC Item Scores**

| PACIC Item | Mean (range) Standard Deviation (n=444) |
|---|---|
| 1. Asked for my ideas when we made a treatment plan (n=434) | 3.11 (1.0 - 5.0) 1.37 |
| 2. Given choices about treatment to think about (n=428) | 3.24 (1.0 – 5.0) 1.37 |
| 3. Asked to talk about any problems with my medicines or their effects (n=431) | 3.45 (1.0 – 5.0) 1.36 |
| 4. Given a written list of things I should do to improve my health (n=438) | 3.09 (1.0 – 5.0) 1.43 |
| 5. Satisfied that my care was well organized (n=434) | 3.72 (1.0 – 5.0) 1.19 |
| 6. Shown how what I did to take care of myself influenced my condition (n=434) | 3.36 (1.0 – 5.0) 1.34 |
| 7. Asked to talk about my goals in caring for my condition (n=434) | 2.95 (1.0 – 5.0) 1.43 |
| 8. Helped to set specific goals to improve my eating or exercise (n=434) | 3.02 (1.0 – 5.0) 1.43 |
| 9. Given a copy of my treatment plan (n=432) | 3.02 (1.0 – 5.0) 1.52 |
| 10. Encouraged to go to a specific group or class to help me cope with my chronic condition (n=434) | 2.78 (1.0 – 5.0) 1.54 |
| 11. Asked questions, either directly or on a survey, about my health habits (n=436) | 3.13 (1.0 – 5.0) 1.44 |
| 12. Sure that my doctor or nurse thought about my values, beliefs, and traditions when they recommended treatments to me (n=436) | 3.41 (1.0 – 5.0) 1.43 |
| 13. Helped to make a treatment plan that I could carry out in my daily life (n=434) | 3.30 (1.0 – 5.0) 1.44 |
| 14. Helped to plan ahead so I could take care of my condition even in hard times (n=436) | 3.08 (1.0 – 5.0) 1.51 |
| 15. Asked how my chronic condition affects my life (n=436) | 3.20 (1.0 – 5.0) 1.49 |
| 16. Contacted after a visit to see how things were going (n=439) | 2.62 (1.0 – 5.0) 1.53 |
| 17. Encouraged to attend programs in the community that could help me (n=433) | 2.24 (1.0 – 5.0) 1.44 |
| 18. Referred to a dietician, health educator, or counselor (n=438) | 2.61 (1.0 – 5.0) 1.50 |
| 19. Told how my visits with other types of doctors, like an eye doctor or other specialist, helped my treatment (n=439) | 2.82 (1.0 – 5.0) 1.53 |
| 20. Asked how my visits with other doctors were going (n=438) | 2.60 (1.0 – 5.0) 1.53 |

addressed to optimize delivery of PCC and increase ratings of care within this patient population. Nearly half of the sample was characterized by lower levels of patient activation. Moreover, our data demonstrate gaps that may exist in delivering follow-up care, enabling patients to set specific goals related to their health, and informing patients about the risks and benefits associated with available treatment options for GERD.

The overarching mission of the PCC model includes delivering high-quality care that is responsive to individual needs, supporting patient engagement in clinical care, and improving communication between patients and the health care system.[24, 40] Given the overlap between PCC and patient experience principles,[26] PRO measures that address PCC concepts may represent an important component to assess patient experiences and capture the perspectives of patients with burdensome, prevalent, and costly diseases.[41] Despite their value in evaluating care across a range of chronic conditions,[42-44] the application of the PROs used in this study has not been previously explored in the area of GERD and remains limited within the broader gastrointestinal (GI) literature. Randell and colleagues[45] previously used the PACIC to assess care perceptions among individuals with inflammatory bowel disease (IBD), finding that respondents achieved lowest scores in the follow-up and coordination of care subscale. This is corroborated by our study, as well as several prior studies describing PACIC scores beyond GI diseases,[46-49] and suggests that continuity of care is an important goal for quality improvement in GERD care. In prior studies exploring patient activation among individuals with IBD and irritable bowel syndrome (IBS), respondents achieved similar PAM scores compared to our sample.[50-51] Given the chronic nature of GERD symptoms and a need for these patients to remain actively engaged throughout the care continuum, the PAM may be especially useful to identify patients with GERD who require additional support to manage their own health in contrast to activated patients who may be well-suited for self-management interventions alone.

Although our results delineate several existing strengths and gaps in the patient experience for Veterans with GERD, recent recommendations highlight a need to optimize use of PROs and translate PRO data into improved clinical practice.[52] Our findings present a number of clinical implications and actionable next steps unique to the care of patients with GERD on PPI therapy. These PRO data can inform how the health care system can better support patients with GERD, including better understanding and enhancing patient activation, risk communication, and follow-up care. One key finding that emerged as a potential deficit within GERD care was the perceived risk communication related to GERD treatments. Despite their benefits to many patients, there is accumulating evidence around a broad range of risks

and side effects associated with PPI use.[18] More recently, widespread press coverage linking PPI use to dementia and chronic kidney disease have led to growing fears and concerns among PPI users.[25, 53-54] Our findings underscore these concerns, and suggest that providers may need to pay particular attention to patients' concerns and better inform patients of the risks and benefits related to PPIs and other GERD therapies. No prior studies have addressed patient experiences or communication in GERD care; however, in a study of outpatient care experiences in a broader GI patient population, Larkins et al found that GI patients perceived the quality of patient-provider interaction to be integral to an optimal patient experience.[55] This may be especially important to consider among GERD patients. Quality improvement efforts may benefit from further engaging patients to determine how patient-provider communication and care processes can be enhanced to address patient concerns and preferences.

Several limitations should be acknowledged. Our survey response rate was lower than expected and may not represent the greater Veteran population with GERD. Moreover, Veterans represent a population that is generally older and less educated compared to the American population overall;[56] thus, our results may not be applicable to the broader population with GERD who use PPIs. The cross-sectional study design allowed us to examine patient perceptions at a given point of time only. Finally, the self-reported nature of our survey data may have introduced additional limitations.

We contribute to existing literature by (1) using PROs to describe how patients with GERD on PPI therapy perceive care, and (2) harnessing patient perspectives that can be used to optimize care experiences to better align with the unique needs and preferences within this population. Our approach may be used by researchers and clinicians to characterize patient experiences among individuals with other chronic diseases beyond GERD. In this study, Veterans with GERD perceived care to be well-organized, supportive in enhancing shared decision-making, and effective in improving their understanding of care. However, several gaps may exist in delivering GERD follow-up care, enhancing patient activation, and informing patients about the risks and benefits of existing treatments. Findings can inform further investigation and development of targeted interventions to enhance the experience of PCC for patients with GERD. Further studies are needed to understand patient- and system-level factors independently associated with higher scores in some PCC domains, including shared decision-making and delivery system design, and lower scores in other domains, including risk communication and follow-up care. Efforts are also needed to explore if PCC outcomes are associated with GERD symptom control, particularly in areas of follow-up support, care coordination and risk communication. This may impact appropriate use of

diagnostic testing and long-term medication use for an increasingly large, complex patient population.

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