Validation of the Patient Activation Measure in kidney stone disease patients

Liam Murad[1], Sophie Abou Samra[2], Ryan Schwartz[2], Anis Assad[3], Kristina Penniston[4], Kahina Bensaadi[5], Malek Meskawi[3], Naeem Bhojani[3]

[1]Faculty of Medicine and Health Sciences, McGill University, Montreal, QC, Canada; [2] Faculty of Medicine, Université de Montréal, Montreal, QC, Canada; [3]Division of Urology, Centre hospitalier de l'Université de Montréal, Montreal, QC, Canada; [4]Department of Urology, University of Wisconsin School of Medicine and Public Health, Madison, WI, United States; [5] Research Center of the University of Montreal Hospital Center, Montreal, QC, Canada

Funding: *This work was supported in part by the 2023 Urology Care Foundation Summer Medical Student Fellowship Program and the Herbert Brendler, MD, Research Fund. Personal funds of the principal investigator were used as well.*

Cite as: Murad L, Samra SA, Schwartz R, et al. Validation of the Patient Activation Measure in kidney stone disease patients. *Can Urol Assoc J* 2024 December 9; Epub ahead of print. http://dx.doi.org/10.5489/cuaj.8944

Published online December 9, 2024

Corresponding author: Dr. Naeem Bhojani, Division of Urology, Centre hospitalier de l'Université de Montréal, Montreal, QC, Canada; naeem.bhojani@gmail.com

***

ABSTRACT

Introduction: We aimed to validate the Patient Activation Measure (PAM) within a kidney stone disease (KSD) population, determine the variability of patient activation within this population, and characterize relationships between activation and variables such as health literacy, quality of life, and demographics.

Methods: This cross-sectional study includes individuals 18 years or older followed for KSD at University of Montreal Hospital Center. Demographic data and responses for the PAM, Wisconsin Stone

KEY MESSAGES

- Patient activation measures a patient's ability to self-manage their health.
- Patient activation has not been explored in the context of kidney stone disease.
- Female sex and poor medication adherence were associated with lower activation.
- Certain aspects of health literacy were associated with higher activation.
- Rasch analysis suggests that multidimensionality may threaten construct validity.

Quality of Life scale, and health literacy questionnaire (HLQ) were acquired.
Results: Females and those with poor medication adherence were found to have significantly lower activation. The HLQ dimensions "Actively managing my health," "Navigating the healthcare system," and "Understand health information well enough to know what to do" were associated with significantly higher activation. Rasch analysis revealed an item reliability of 0.81, a person reliability of 0.98, and a Cronbach's alpha of 0.88. Regarding item fit, only item 1 (When all is said and done, I am the person who is responsible for taking care of my health) fit poorly with the model. Principle component analysis revealed evidence of a second dimension, accounting for 9.0% of the variation in observed responses.
Conclusions: Female sex and poor medication adherence were associated with significantly lower activation. Aspects of health literacy concurring with the precise definition of "activation" were associated with significantly higher PAM scores. The PAM was found to have good person and item reliability, and good internal consistency; however, principal component analysis revealed that construct validity is possibly threatened by multidimensionality.

INTRODUCTION

Healthcare providers face a significant challenge when encouraging individuals to engage in health-related behaviors for managing chronic illness. This has been exemplified in the case of kidney stone disease (KSD), where patient compliance with the CUA's preventative best practice guidelines is poor.[1] Research suggests that up to half of KSD patients experience recurrent renal stones within five years of initial stone formation, with recurrence frequency typically escalating with each subsequent relapse.[2,3]. Lifestyle changes can reduce stone recurrence but are heavily reliant upon one's awareness of the severity of their condition.[4] For KSD specifically, poor adherence to preventative guidelines is attributed to a lack of perceived disease severity.[1] Low socioeconomic status further complicates disease management, as it is associated with greater disease burden, and lower disease-specific quality of life (QOL).[5]

Activation is a metric t hat quantifies patient capacity for self-management. An "activated" patient can self-manage health problems, engage in activities that maintain healthy functioning, and involve themselves in treatment and diagnostic choices. For example, patients with higher activation are more likely to exercise, have a better diet, and engage in consumeristic health behaviors.[6,7] Studies in other disease populations have demonstrated that higher activation is predictive of effective pain management and better health outcomes.[8,9]

Quantifying activation has significant implications for patients, enabling tailored interventions to match their needs and abilities.[6] Because less activated patients may feel overwhelmed with their treatment regimen, activation status can help tailor interventions to focus on areas needing the most support.[10] Changes in activation can also gauge intervention

effectiveness. Studies show that targeted interventions can increase patient activation and improve behaviors, practices, and clinical outcomes.[11] Similarly, contrasting activation changes between groups receiving different interventions enables researchers to assess the relative efficacy of multiple approaches.[12]

The Patient Activation Measure

The Patient Activation Measure (PAM) is an interval-level, unidimensional, Guttman-like measure that was developed using Rasch modeling in order to reliably measure activation.[6] Rasch analysis is a form of item-response theory that is based on latent trait modeling and can establish how well the modeled measure is supported by the scores of those who use the instrument that is being assessed.

The PAM will score an individual's activation on a scale of 0 to 100, and depending on that score, will place them in one of four levels (Table 1).[13] At the lowest level, patients are overwhelmed at the prospect of managing their health and lack confidence in their ability to self-manage. At level two, patients start to become aware of the role that they have in managing their health but struggle to set goals for themselves. Patients who attain a PAM level of three are goal-oriented and capable of taking action to improve their health. Finally, patients who are at the fourth, and highest level attainable, can reliably engage in healthy practices but may struggle to maintain these healthy practices in times of stress.[14]

This tool has been utilized for many chronic diseases, including asthma, chronic pain, and COPD. It has also been revalidated in multiple sclerosis (MS), heart failure, coronary artery disease, diabetes, and CKD patient populations.[7,9,14–18] Although the PAM has been validated and utilized in other chronic disease populations, it has not been validated in a population of KSD patients, nor have the relationships between PAM and other predictors been explored. KSD is different from other chronic diseases in that the disease burden is unpredictable insofar as the frequency of its presentation. To determine whether the PAM is useful for KSD patients, validating the PAM in this population is essential. This study aims to validate the PAM in KSD patients and explore its potential correlations with demographics, QOL, and health literacy.

METHODS

Participants

For the study, 200 individuals 18 years or older who currently have, or have had, kidney stones were recruited from the University of Montreal Health Center KSD clinic. Those having an active stone event, unable to follow preventative guidelines, unable to consent, or unable to complete the questionnaire were ineligible to participate.

Measures

A demographic questionnaire posed questions on age, biological sex assigned at birth, race, marital status, education, employment, household income, and medication adherence (Table 2).

The remainder consisted of the 13-item PAM questionnaire (PAM-13), the Wisconsin Stone Quality of Life Scale (WISQOL), and the Health Literacy Questionnaire (HLQ). English and French versions all questionnaires were used based on participant preferences. Time followed by urologist was also considered.

The PAM-13 is an abridged version of the original 22-item version.[6] Items are answered on a Likert scale. PAM levels of 1, 2, 3, and 4 correspond to PAM score intervals of 0.0 – 47.0, 47.1 – 55.1, 55.2 – 72.4, and 72.5 – 100.0, respectively, corresponding to lower or higher patient self-efficacy (activation).

The WISQOL assesses health-related QOL of patients with KSD.[19] Study participants were queried on disease-specific QOL over the past month. Full responses allow for the calculation of Social impact, Emotional impact, Disease impact, Impact on vitality, and an overall score. Results of each sub-domain as well as total score may be standardized to a 0-100 scale, corresponding to the lowest (worst) and highest (best) QOL, thus enabling comparisons to other instruments that are scored on a 0-100 scale.

The HLQ consists of 9 dimensions that can be administered independently.[20] Dimensions 3 (Actively managing my health), 7 (Navigating the healthcare system), 8 (Ability to find good health information), and 9 (Understanding health information well enough to know what to do) were used.

Statistical analysis

Predictors of activation were estimated using a multivariable linear regression (MLR) after forward stepwise variable selection using Akaike Information Criterion. 36 participants were excluded from this analysis due to incomplete data. Categorical variables were included in this analysis. The following subgroups were used to ensure an adequate sample size:

- Race: White and Non-White
- Marital status: Married/Living with partner, Single/Never married, and Separated/Widowed/Divorced
- Education: Highschool diploma, College diploma, Bachelors, Masters, and Doctorate/PhD/Professional Diploma
- Employment: Full-time, Retired, and Part-time/Unemployed/Invalid
- Adherence: Never, and Rarely/Often/Very often

Statistical analyses were performed using R version 4.3.3 with R Studio. ANOVA was used to calculate p-values for continuous variables, and chi-square tests were used for categorical variables (Table 2).

The PAM was assessed for unidimensionality, reliability, and item fit using Winsteps Rasch Modelling software version 5.7.1.0.[21] All 200 respondents were included in this analysis. Item-fit with the Rasch model was examined using the mean-square residual goodness of fit statistics INFIT (inlier-sensitive fit), and OUTFIT (outlier-sensitive fit). Item fit statistics between 0.5 and 1.5 are adequate, however, the acceptable lower and upper limits of these

statistics in the literature are commonly found to be 0.7 and 1.3.[21,22] Principal component analysis (PCA) of linearized Rasch residuals was performed to assess unidimensionality and local dependence of scale items.

Those who consented to participate were sent the questionnaire 24-48 hours after their consult to control for transient increases in activation after urology consultations or any deviations in adherence to healthy practices.

RESULTS

Population characteristics

Population demographics were determined (Table 2). PAM scores for the 200-respondent sample ranged between 40.7 and 100.0, with a mean of 66.6 (SD = 14.4). The PAM scores of 17 respondents (8.5%) had an activation level of 1, the lowest level. Other respondents scored in level 2 (n=24, 12.0%), level 3 (n=91, 45.5%), and level 4 (n=68, 34%).

Activation and other variables

Relationships between activation and other variables were determined using data from the 164 participants who had full questionnaire responses. Pearson correlation coefficients were calculated and are shown (Table 3). All HLQ dimensions were found to be significantly correlated to PAM score (all $p < 0.05$), however, QOL was not.

MLR revealed that only sex and medication adherence were associated with PAM score. Females were found to have significantly lower PAM levels and scored 5.06 points lower than males (95% CI: [-9.48 – -0.64], $p < 0.05$). Those who missed doses of medication at any frequency scored 5.02 points lower (95% CI: [-9.59 – -0.45], $p < 0.05$). HLQ Dimensions 3, 7, and 9 – but not dimension 8 – were all found to be associated with a significantly higher PAM score. QOL was not associated with activation (Table 4).

Rasch analysis

The PAM was found to have a high person reliability coefficient of 0.81 and a person separation index of 2.09. It was also found to have a high item reliability coefficient of 0.98 and an item separation index of 6.99. Cronbach's alpha was found to be 0.88, indicating good internal consistency and therefore high test reliability.

All items had INFIT and OUTFIT statistics within the range of 0.7 and 1.3, except for items 1 and 4 (Table 5).

PCA revealed that 44.7% of the variance in the observed responses was explained by the respondents (26.0%) and items (18.7%) combined, and the remaining 55.3% was explained by other unknown sources of variation. The first contrast was found to have an eigenvalue of 2.11 and explained 9.0% of the variation in observed responses. Items 10 and 13 were found to have loadings of 0.61 and 0.63 on the first contrast, which were higher than all other items. The

residuals of items 10 and 13 were found to be weakly correlated (r = 0.39), and therefore possibly locally dependent.

DISCUSSION

Activation and other variables

The PAM scores among this patient population were high, with approximately 80% of all participants falling into PAM levels 3 or 4. This high proportion of highly activated patients can likely be attributed to the fact that these patients regularly attend clinic appointments, indicating a higher likelihood of being actively involved in managing their disease than those not being followed. Individuals suffering from KSD who are not followed regularly may have lower activation, and consequently lower health literacy, lower quality of life, and greater disease burden.

Study findings regarding PAM level distribution are comparable to those found in an MS population.[14] However, it is important to note that other studies have found that patients suffering from chronic disease mostly have lower activation and that PAM levels can vary for different chronic diseases.[23,24] Given the absence of research on patient activation in KSD, it is not possible to draw comparisons between different populations within this disease.

With regards to demographic predictors of PAM score, females were found to have significantly lower activation. One study from a different chronic disease population has found that there is no difference between sexes, and another found that women are more activated.[25,26] It is evident from these varied findings that there is no absolute answer as to whether males or females are more activated than the other. In the case of KSD however, it is noteworthy that stones are more prevalent in males. It is possible that because of this, males are more motivated to learn about this disease and optimize their functioning.[27] This however is only speculation and underscores the gap in existing literature regarding patient activation in KSD patients. As for medication adherence, patients who were self-reported to miss medication doses at any frequency were found to have significantly lower PAM scores. Similar findings have been reported in the past, with PAM score being significantly related to medication adherence.[28]

While older age has been linked to lower activation, determining the age-activation relationship for KSD may be challenging due to its lower prevalence in younger individuals.[27] It can be similarly difficult for other demographic characteristics as well since they are often not mutually independent. For instance, while one study did not find a significant direct effect between race and activation, it did find that racial disparities in activation could be mediated by a lack of health literacy.[29] Another study found that income and difficulty paying monthly bills mediated the relationship between race and activation, whereas health literacy and education did not.[30]

Previous studies have reported that QOL is correlated with patient activation.[7,14] Interestingly, this patient population didn't exhibit such observations. This is likely because

KSD, though prone to relapse, doesn't consistently burden QOL as immediately as chronic conditions such as CHF, COPD, and CKD. A longitudinal study could better explore WISQOL score variations over time and their relation to activation, as this study only provides a snapshot of patient experiences during questionnaire completion. Given KSD's variable disease burden, further research should investigate temporal changes in PAM and QOL, as well as how different factors impacting QOL relate to patient activation.

Although all HLQ dimensions assessed were correlated with activation, only HLQ dimensions 3, 7, and 9 were found to be associated with higher activation. Activated individuals are defined as believing patients play a critical role in self-managing care (HLQ dimension 3); collaborating with their health providers and accessing appropriate and high-quality care (HLQ dimension 7); and possessing the skills and behavioral repertoire to manage their condition and maintain functioning (HLQ dimension 9).[6] All four domains are correlated to activation as they are all components of health literacy, which is known to be correlated with activation.[29,31] However, only the HLQ dimensions that concur precisely with the definition of activation were found to actually be associated with higher PAM scores. HLQ dimension 8 was not, as the ability to find good health information was never stated to be a specific characteristic of a well-activated patient.[6]

Rasch analysis

All items had fit statistics within the accepted range except for items 1 and 4. Item 4 raises little concern as its observed fit statistics border the acceptable interval, but still fall in the broader 0.5 to 1.5 range. Conversely, item 1 had INFIT and OUTFIT statistics of 1.42 and 1.86, indicating that it fits poorly compared to the other questionnaire items. Interestingly, this was also observed in another study that explored activation in MS patients.[13] Given the unpredictability of KSD and MS relapse, different patients are likely to have substantially different experiences managing their health concerns.[13] It is therefore not surprising that of all the items in the PAM, this is the only one that fell so far beyond the acceptable range of fit statistics.

High person reliability (0.81) suggests the PAM effectively distinguished between proficient and non-proficient questionnaire performers. A person separation index of 2.09 indicates at least 2 levels of ability differentiated by the model.[20] Item reliability was also high (0.98), indicating the Rasch model confirmed varying item difficulties. This aligns with the PAM's design as a Guttman-like measure, where items become progressively more difficult.[6] An item separation index of 6.99 indicates at least 7 levels of item difficulty differentiated by the model.[20]

PCA suggests that the PAM may not be unidimensional, indicating a potential second measurable latent trait. This is supported by the substantial unexplained variation in responses (55.3%). Residual analysis revealed a second dimension, with the first contrast showing an eigenvalue of 2.11, suggesting that about 2 questionnaire items may form their own structure. Items 10 and 13 contributed most significantly to this dimension, with correlated residuals,

suggesting a compromise in the local independence of scale items. Interestingly, these items have almost identical wording, querying respondents on their ability to maintain lifestyle changes such as dietary modification and exercise. Therefore, these two questions may measure a separate latent trait, such as health locus of control, perceived control over one's health, or stress management capabilities, none of which are the same as activation. Further research must determine the extent to which this misrepresents reported activation levels for individuals in this population, and whether different KSD patient populations demonstrate this phenomenon.

Finally, Cronbach's alpha was found to be 0.88, which indicates good internal consistency for the measure. Because evidence of another dimension was found, however, it is possible that Cronbach's alpha is providing an inaccurate measure of the test's internal consistency.

Clinical implementation

The PAM has been used clinically for tailoring interventions to patients' unique needs and abilities.[6] In the case of KSD, those with higher activation could receive detailed nutritional counseling to proactively prevent stone formation, while those with lower activation receive simplified guidance and frequent follow-ups to ensure adherence.

Additionally, changes in PAM score on an individual level can indicate patient progress and readiness for more advanced self-management strategies, while changes in PAM score between groups can gauge efficacy of specific interventions applied to each group.

There is potential for the PAM to be used in a clinical setting, but it requires further investigation in larger, more diverse patient populations.

Limitations

The study findings are limited insofar as their generalizability, given that patients from a single center were used. The study population had little representation from ethnic minorities, information on disease severity and duration of illness was not collected, and respondents were not queried on their comorbidities which could influence health literacy, QOL, and activation. Also, participants' proficiency in English or French wasn't assessed. While they could choose to respond in either language, these may not have been their native languages. Since the study was conducted in a region where English and French are the dominant languages, it is unlikely this affected the results. PAM scores may also be disproportionately higher in this population given that surgeons working at university centers have greater expertise, which can affect the quality of patient education. As per the sample size used for the analysis of activation and demographic data, 164 may not suffice for drawing meaningful and generalizable conclusions. For regression analysis, variable subgroups were consolidated to ensure sufficient sample size. Additionally, a cross-sectional study may not allow for a meaningful relationship between activation and QOL to be drawn. Lastly, although the questionnaire was sent to study participants within 48 hours

after their urology consultation, there was no way of ensuring that respondents would complete the questionnaire promptly after it was sent to them.

CONCLUSION

The goal of this study was to provide an initial overview of patient activation for patients suffering from KSD and to validate whether the PAM, as it is in its current state, can reliably assess patient activation for these patients. The PAM had good person and item reliability, and good item fit, except for item 1. The PAM exhibited signs of being non-unidimensional, with items 10 and 13 seeming to form their own structure within the scale. Future studies should focus on determining the significance of this finding, and whether it is reproducible in other KSD populations.

Of the demographic information collected, missed doses of medication and female sex were associated with significantly lower PAM scores. Other demographic variables were not associated with activation. Larger observational studies across different centers and patient populations need to be undertaken to better characterize the patterns and relationship between activation, QOL, health literacy, and demographics for this disease.

REFERENCES

1. Bos D, Kim K, Hoogenes J, et al. Compliance of the recurrent renal stone former with current best practice guidelines. *Can Urol Assoc J* 2018;12:E112-20. https://doi.org/10.5489/cuaj.4605
2. Lotan Y, Cadeddu JA, Roerhborn CG, et al. Cost-effectiveness of medical management strategies for nephrolithiasis. *J Urol* 2004;172:2275-81. https://doi.org/10.1097/01.ju.0000141498.11720.20
3. Strauss AL, Coe FL, Deutsch L, et al. Factors that predict relapse of calcium nephrolithiasis during treatment: A prospective study. *Am J Med* 1982;72:17-24. https://doi.org/10.1016/0002-9343(82)90566-6
4. DiMatteo MR, Haskard KB, Williams SL. Health beliefs, disease severity, and patient adherence: A meta-analysis. *Med Care* 2007;45:521. https://doi.org/10.1097/MLR.0b013e318032937e
5. Scotland KB, Armas-Phan M, Dominique G, et al. Social determinants of kidney stone disease: The impact of race, income and access on urolithiasis treatment and outcomes. *Urology* 2022;163:190-5. https://doi.org/10.1016/j.urology.2021.08.037
6. Hibbard JH, Stockard J, Mahoney ER, et al. Development of the patient activation measure (PAM): Conceptualizing and measuring activation in patients and consumers. *Health Serv Res* 2004;39:1005-26. https://doi.org/10.1111/j.1475-6773.2004.00269.x
7. Mosen DM, Schmittdiel J, Hibbard J, et al. Is patient activation associated with outcomes of care for adults with chronic conditions? *J Ambulatory Care Manage* 2007;30:21-9. https://doi.org/10.1097/00004479-200701000-00005
8. Manias E, Williams A. Managing pain in chronic kidney disease: Patient participation in decision-making. *J Adv Nurs* 2008;61:201-10. https://doi.org/10.1111/j.1365-2648.2007.04488.x
9. Shnaigat M, Downie S, Hosseinzadeh H. Effectiveness of patient activation interventions on chronic obstructive pulmonary disease self-management outcomes: A systematic review. *Aust J Rural Health* 2022;30:8-21. https://doi.org/10.1111/ajr.12828
10. Hibbard JH, Greene J. What the evidence shows about patient activation: Better health outcomes and care experiences; fewer data on costs. *Health Aff Proj Hope* 2013;32:207-14. https://doi.org/10.1377/hlthaff.2012.1061
11. Hibbard JH. Patient activation and the use of information to support informed health decisions. *Patient Educ Couns* 2017;100:5-7. https://doi.org/10.1016/j.pec.2016.07.006
12. Knudsen MV, Petersen AK, Angel S, et al. Tele-rehabilitation and hospital-based cardiac rehabilitation are comparable in increasing patient activation and health literacy: A pilot study. *Eur J Cardiovasc Nurs* 2020;19:376-85. https://doi.org/10.1177/1474515119885325

13. Fisher J. 10 Strategies to Increase Patient Activation [Internet]. Phreesia. 2022. Available at: https://www.phreesia.com/10-strategies-to-increase-patient-activation/. Accessed Sept. 14, 2024
14. Stepleman L, Rutter MC, Hibbard J, et al. Validation of the patient activation measure in a multiple sclerosis clinic sample and implications for care. *Disabil Rehabil* 2010;32:1558-67. https://doi.org/10.3109/09638280903567885
15. Lunardi LE, Hill K, Xu Q, et al. The effectiveness of patient activation interventions in adults with chronic kidney disease: A systematic review and meta-analysis. *Worldviews Evid Based Nurs* 2023;20:238-58. https://doi.org/10.1111/wvn.12634
16. Ngooi BX, Packer TL, Kephart G, et al. Validation of the Patient Activation Measure (PAM-13) among adults with cardiac conditions in Singapore. *Qual Life Res Int J Qual Life Asp Treat Care Rehabil* 2017;26:1071-80. https://doi.org/10.1007/s11136-016-1412-5
17. Laranjo L, Dias V, Nunes C, et al. Translation and validation of the Patient Activation Measure in Portuguese people with type 2 diabetes Mellitus. *Acta Med Port* 2018;31:382-90. https://doi.org/10.20344/amp.9072
18. Lightfoot CJ, Wilkinson TJ, Memory KE, et al. Reliability and validity of the Patient Activation Measure in kidney disease: Results of Rasch analysis. *Clin J Am Soc Nephrol CJASN* 2021;16:880-8. https://doi.org/10.2215/CJN.19611220
19. Penniston KL, Antonelli JA, Viprakasit DP, et al. Validation and reliability of the Wisconsin Stone Quality of Life Questionnaire. *J Urol* 2017;197:1280-8. https://doi.org/10.1016/j.juro.2016.11.097
20. Osborne RH, Batterham RW, Elsworth GR, et al. The grounded psychometric development and initial validation of the Health Literacy Questionnaire (HLQ). *BMC Public Health* 2013;13:658. https://doi.org/10.1186/1471-2458-13-658
21. Linacre JM. A user's guide to WINSTEPS® MINISTEP: Rasch-model computer programs. Available at: www.winsteps.com/manuals.htm. Accessed Sept. 14, 2024
22. Müller M. Item fit statistics for Rasch analysis: Can we trust them? *J Stat Distrib Appl* 2020;7:5. https://doi.org/10.1186/s40488-020-00108-7
23. Skolasky RL, Green AF, Scharfstein D, et al. Psychometric properties of the Patient Activation Measure among multimorbid older adults. *Health Serv Res* 2011;46:457. https://doi.org/10.1111/j.1475-6773.2010.01210.x
24. Tusa N, Kautiainen H, Elfving P, et al. Relationship between patient activation measurement and self-rated health in patients with chronic diseases. *BMC Fam Pract* 2020;21. https://doi.org/10.1186/s12875-020-01301-y
25. Hendriks SH, Hartog LC, Groenier KH, et al. Patient activation in Type 2 diabetes: Does it differ between men and women? *J Diabetes Res* 2016;2016:7386532. https://doi.org/10.1155/2016/7386532

26. Hernar I, Graue M, Igland J, et al. Patient activation in adults attending appointments in general practice: A cross-sectional study. *BMC Prim Care* 2023;24:144. https://doi.org/10.1186/s12875-023-02102-9
27. Ordon M, Powers AL, Chew BH, et al. Incidence and trends in the treatment of kidney stones in Canada: A population-based cohort study. *Can Urol Assoc J* 2024;18:158-64. https://doi.org/10.5489/cuaj.8596
28. Caballero J, Patel N, Waldrop D, et al. Patient activation and medication adherence in adults. *J Am Pharm Assoc* 2024;64:102025. https://doi.org/10.1016/j.japh.2024.01.021
29. Gwynn KB, Winter MR, Cabral HJ, et al. Racial disparities in patient activation: Evaluating the mediating role of health literacy with path analyses. *Patient Educ Couns* 2016;99:1033-7. https://doi.org/10.1016/j.pec.2015.12.020
30. Holt JM, Winn A, Cusatis R, et al. Racial disparities in patient activation: The role of economic diversity. *West J Nurs Res* 2021;43:517-29. https://doi.org/10.1177/0193945920963130
31. Smith SG, Curtis LM, Wardle J, et al. Skill set or mind set? Associations between health literacy, patient activation and health. *PloS One* 2013;8:e74373. https://doi.org/10.1371/journal.pone.0074373

Disclosures:

Dr Murad is an awardee of the 2023-2024 AUA Summer Medical Student Fellowship. Dr. Bhojani is a consultant for Boston Scientific, Olympus, and Procept Biorobotics.

FIGURES AND TABLES

Table 1. PAM level definitions[13]	
PAM level	**Definition**
PAM level 1: "Disengaged and overwhelmed"	Individuals tend to be passive and lack confidence. Their healthcare knowledge is limited, they have weak goal orientation, and their adherence to suggested treatment regimens is poor.
PAM level 2: "Becoming aware but still struggling"	People possess some knowledge about healthcare, but significant gaps still exist. They feel that their health is mostly beyond their control but are capable of setting basic goals.
PAM level 3: "Taking action & gaining control"	People have essential information and are developing self-management skills. They aim to follow best practices and are focused on achieving goals.
PAM level 4: "Maintaining behaviors and pushing further"	Individuals have embraced new habits but may struggle when faced with stress or change. Prioritizing a healthy lifestyle remains important.

PAM: Patient Activation Measure.

Table 2. Population summary						
	PAM level 1 (n=17)	**PAM level 2 (n=24)**	**PAM level 3 (n=91)**	**PAM level 4 (n=68)**	**Total (n=200)**	**p**
Sex						0.910
Male	11 (64.7%)	15 (62.5%)	54 (59.3%)	44 (64.7%)	124 (62.0%)	
Female	6 (35.3%)	9 (37.5%)	37 (40.7%)	24 (35.3%)	76 (38.0%)	
Age						0.400
Median [Q1, Q3]	58.0 [40.0, 64.0]	64.5 [53.5, 71.0]	57.0 [46.5, 66.0]	60.0 [43.0, 67.0]	58.0 [45.0, 67.0]	
PAM score						< 0.001
Mean (SD)	44.7 (2.10)	51.2 (1.79)	62.7 (4.47)	82.6 (10.1)	66.6 (14.4)	
Race						0.157
White, not Hispanic/Latino	12 (70.6%)	16 (66.7%)	71 (78.0%)	45 (66.2%)	144 (72.0%)	

White, Hispanic/Latino	2 (11.8%)	2 (8.3%)	2 (2.2%)	3 (4.4%)	9 (4.5%)	
Middle-Eastern	1 (5.9%)	1 (4.2%)	3 (3.3%)	1 (1.5%)	6 (3.0%)	
African American	0 (0%)	0 (0%)	0 (0%)	2 (2.9%)	2 (1.0%)	
Aboriginal	1 (5.9%)	0 (0%)	0 (0%)	0 (0%)	1 (0.5%)	
South-Asian	0 (0%)	0 (0%)	0 (0%)	1 (1.5%)	1 (0.5%)	
Other	1 (5.9%)	5 (20.8%)	12 (13.2%)	15 (22.1%)	33 (16.5%)	
I would rather not say	0 (0%)	0 (0%)	3 (3.3%)	1 (1.5%)	4 (2.0%)	
Marital status						0.576
Married	7 (41.2%)	7 (29.2%)	33 (36.3%)	36 (52.9%)	83 (41.5%)	
Living with a partner	6 (35.3%)	6 (25.0%)	23 (25.3%)	12 (17.6%)	47 (23.5%)	
Separated	0 (0%)	0 (0%)	1 (1.1%)	2 (2.9%)	3 (1.5%)	
Divorced	2 (11.8%)	3 (12.5%)	9 (9.9%)	4 (5.9%)	18 (9.0%)	
Single/Never Married	2 (11.8%)	6 (25.0%)	20 (22.0%)	14 (20.6%)	42 (21.0%)	
Widowed	0 (0%)	2 (8.3%)	4 (4.4%)	0 (0%)	6 (3.0%)	
I would rather not say	0 (0%)	0 (0%)	1 (1.1%)	0 (0%)	1 (0.5%)	
Highest attained level of education						0.603
High school diploma	2 (11.8%)	7 (29.2%)	16 (17.6%)	9 (13.2%)	34 (17.0%)	
College diploma	6 (35.3%)	6 (25.0%)	21 (23.1%)	16 (23.5%)	49 (24.5%)	
Bachelors	3 (17.6%)	4 (16.7%)	32 (35.2%)	16 (23.5%)	55 (27.5%)	
Masters	4 (23.5%)	4 (16.7%)	12 (13.2%)	16 (23.5%)	36 (18.0%)	
Doctorate/PhD	0 (0%)	2 (8.3%)	2 (2.2%)	2 (2.9%)	6 (3.0%)	
Professional diploma (JD, MD, etc.)	1 (5.9%)	1 (4.2%)	3 (3.3%)	4 (5.9%)	9 (4.5%)	
I would rather not say	1 (5.9%)	0 (0%)	5 (5.5%)	5 (7.4%)	11 (5.5%)	
Employment status						0.262
Full-time	9 (52.9%)	7 (29.2%)	49 (53.8%)	35 (51.5%)	100 (50.0%)	
Part-time	0 (0%)	1 (4.2%)	5 (5.5%)	7 (10.3%)	13 (6.5%)	
Retired	7 (41.2%)	15 (62.5%)	29 (31.9%)	20 (29.4%)	71 (35.5%)	
Unemployed	0 (0%)	0 (0%)	2 (2.2%)	2 (2.9%)	4 (2.0%)	
Invalid (cannot work)	1 (5.9%)	0 (0%)	6 (6.6%)	3 (4.4%)	10 (5.0%)	
I would rather not say	0 (0%)	1 (4.2%)	0 (0%)	1 (1.5%)	2 (1.0%)	
Annual household income						0.785
<$25 000	0 (0%)	4 (16.7%)	14 (15.4%)	7 (10.3%)	25 (12.5%)	
$25 000–50 000	2 (11.8%)	4 (16.7%)	8 (8.8%)	12 (17.6%)	26 (13.0%)	
$50 000–100 000	4 (23.5%)	7 (29.2%)	23 (25.3%)	18 (26.5%)	52 (26.0%)	
$100 000–200 000	5 (29.4%)	4 (16.7%)	28 (30.8%)	19 (27.9%)	56 (28.0%)	

>$200 000	2 (11.8%)	2 (8.3%)	9 (9.9%)	6 (8.8%)	19 (9.5%)	
I would rather not say	4 (23.5%)	3 (12.5%)	9 (9.9%)	6 (8.8%)	22 (11.0%)	
Frequency of missed doses of medication						0.222
Never	4 (23.5%)	3 (12.5%)	29 (31.9%)	30 (44.1%)	66 (33.0%)	
Rarely	11 (64.7%)	17 (70.8%)	50 (54.9%)	34 (50.0%)	112 (56.0%)	
Often	0 (0%)	1 (4.2%)	4 (4.4%)	0 (0%)	5 (2.5%)	
Very often	0 (0%)	0 (0%)	2 (2.2%)	0 (0%)	2 (1.0%)	
I would rather not say	2 (11.8%)	3 (12.5%)	6 (6.6%)	4 (5.9%)	15 (7.5%)	

PAM: Patient Activation Measure; SD: standard deviation.

Table 3. Correlations between PAM-13 and other validity measures

			Dimensions of Health Literacy				Dimensions of QoL[e]				
		PAM score	HLQ dim 3[a]	HLQ dim 7[b]	HLQ dim 8[c]	HLQ dim 9[d]	Social impact	Emotional impact	Disease impact	Impact on vitality	Overall QoL[e]
	PAM score	–	0.243 (0.002)	0.281 *(<0.001)*	0.210 *(0.007)*	0.297 *(<0.001)*	0.021 *(0.790)*	0.113 *(0.150)*	0.032 *(0.685)*	0.141 *(0.072)*	0.082 *(0.297)*
Dimensions of health	HLQ dim 3[a]		–	0.109 *(0.166)*	-0.059 *(0.450)*	0.070 *(0.375)*	-0.014 *(0.854)*	-0.001 *(0.992)*	0.029 *0(.709)*	0.216 *(0.006)*	0.042 *(0.592)*
	HLQ bim 7[b]			–	0.472 *(<0.001)*	0.353 *(<0.001)*	0.049 *(0.533)*	0.090 *(0.253)*	0.029 *(0.713)*	0.095 *(0.228)*	0.071 *(0.366)*
	HLQ dim 8[c]				–	0.401 *(<0.001)*	0.072 *(0.357)*	0.145 *(0.064)*	0.064 *(0.419)*	0.091 *(0.244)*	0.107 *(0.173)*
	HLQ dim 9[d]					–	0.074 *(0.348)*	0.066 *(0.399)*	0.106 *(0.177)*	0.180 *(0.021)*	0.117 *(0.137)*
Dimensions of QoL[e]	Social impact						–	0.784 *(<0.001)*	0.767 *(<0.001)*	0.561 *(<0.001)*	0.920 *(<0.001)*
	Emotional impact							–	0.701 *(<0.001)*	0.550 *(<0.001)*	0.894 *(<0.001)*
	Disease impact								–	0.588 *(<0.001)*	0.902 *(<0.001)*
	Impact on vitality									–	0.706 *(<0.001)*
	Overall QoL[e]										–
			Computed correlation used Pearson method with listwise-deletion.								

[a] Health literacy questionnaire dimension 3: Actively managing my health; [b]Health literacy questionnaire dimension 7: Navigating the healthcare system; [c] Health literacy questionnaire dimension 8: Ability to find good health information; [d]Health literacy questionnaire dimension 9: Understanding health information well enough to know what to do. PAM: Patient Activation Measure; QoL: quality of life.

Table 4. Multivariable linear regression of predictors of PAM score

		PAM score		
	Predictors	**Estimates**	**CI**	**p**
	(Intercept)	21.46	1.98–40.94	**0.031**
HLQ scores				
	HLQ dimension 3[a]	6.59	2.11–11.07	**0.004**
	HLQ dimension 7[b]	3.23	0.62–5.84	**0.016**
	HLQ dimension 9[c]	5.38	1.50–9.25	**0.007**
Sex				
	Male	–	–	**-**
	Female	-5.06	-9.48– -0.64	**0.025**
Missed doses of medication				
	Never	–	–	**-**
	Rarely/often/very often	-5.02	-9.59– -0.45	**0.032**
	I would rather not say	-6.68	-14.87–1.51	0.109
	Observations	164		
	R^2/R^2 adjusted	0.216/0.186		

[a]Health literacy questionnaire dimension 3: Actively managing my health; [b]Health literacy questionnaire dimension 7: Navigating the healthcare system; [c]Health literacy questionnaire dimension 9: Understanding health information well enough to know what to do. PAM: Patient Activation Measure.

Table 5. PAM-13 with item calibrations for KSD population				
Item	**Calibration[a]**	**Standard error measure[b]**	**INFIT[c]**	**OUTFIT[d]**
1. When all is said and done, I am the person who is responsible for taking care of my health.	35.13	1.28	1.42	1.86
2. Taking an active role in my own health care is the most important thing that affects my health.	37.65	1.20	0.98	0.91
3. I am confident I can help prevent or reduce problems associated with my health.	42.57	1.11	1.05	1.04
4. I know what each of my prescribed medications do.	52.63	0.99	1.31	1.32
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.	48.20	1.02	0.91	0.91
6. I am confident that I can tell a doctor concerns I have even when he or she does not ask.	42.35	1.10	1.23	1.10
7. I am confident that I can follow through on medical treatments I may need to do at home.	43.13	1.10	0.73	0.90
8. I understand my health problems and what causes them.	56.28	0.95	1.08	1.07
9. I know what treatments are available for my health problems.	53.52	0.98	0.95	0.91
10. I have been able to maintain (keep up with) lifestyle changes, like eating right or exercising.	53.26	0.98	1.01	1.00
11. I know how to prevent problems with my health.	55.82	0.95	0.77	0.77
12. I am confident I can figure out solutions when new problems arise with my health.	61.66	0.91	0.80	0.81
13. I am confident that I can maintain lifestyle changes, like eating right	54.16	0.97	0.96	0.97

and exercising, even during times of stress.				

The entire 200-respondent population was used for this analysis. [a] Calibration is a measure of item difficulty and corresponds to level of activation that is required in order to endorse the item. Item measure outputs from Winsteps were rescaled from a scale of 0 to 100 in order to generate these item calibrations. [b]Standard error measure corresponds to the precision of item difficulty estimation. It reflects the standard error of measurement in the estimation of item calibrations. [c]INFIT is the inlier-sensitive fit statistic. This is an information-weighted residual of observed responses from model expected responses, and is sensitive to unexpected patterns of observation close to a person's scale location. [d]OUTFIT is the outlier-sensitive fit statistic. It is more sensitive to unexpected observations by persons on items that are relatively easy or difficult for them, and therefore far from their scale location. PAM: Patient Activation Measure