Evaluating the Relationship between Patient Activation and Health-related Quality of Life (HRQOL) in Patients with Pancreatic Cancer (PwPC)

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Abstract

Purpose: Advanced pancreatic cancer is synonymous with a high mortality rate, debilitating symptom profile, and minimal prolongation in overall survival. Therefore, health-related quality of life (HRQOL) is important in patients with pancreatic cancer (PwPC). In chronic conditions patient activation is positively associated and higher HRQOL. However, no known study has evaluated patient activation, HRQOL, and their association in PwPC.

Methods: A 43-item cross-sectional survey assessed patient activation and HRQOL of patients with locally advanced and metastatic pancreatic cancer undergoing chemotherapy. Variables were analyzed descriptively, and relationships were assessed using bivariate statistics (*sig p <0.05*).

Results: 56 patients participating in the study had an average age of 69.5±11.1 years, and the majority were females (51.8%), Caucasians (61.8%), married/partnered (64.3%) and had at least a college degree (59%). Almost half were at stage 4 (48.2%), and most were newly diagnosed (66.1%). Mean patient activation score was 63.5±17.2 (scale range: 0-100), with most at higher activation levels of 3 or 4 (66.7%). Mean HRQOL score of 41.0±12.7 (scale range: 0-72) was low. Patient activation levels, age, education level, and gender explained 21% of variation in overall HRQOL scores. Patients at activation level 4 had significantly higher overall HRQOL versus those at lower activation (level 1 or 2). Higher patient activation was significantly associated with having either private insurance only or multiple insurances and being partnered.

Conclusion: Patient activation significantly predicted HRQOL in PwPC despite the low sample size. Initiatives to increase patient activation should focus on patients of low socioeconomic status and those without partner support.

Introduction

Pancreatic cancer (PaCa) originates as an abnormal growth of ductal epithelium cells and evolves into invasive cancer. [1] The symptoms and clinical manifestations of pancreatic cancer are location and stage dependent. Common clinical manifestations include obstructive cholestasis, obstructive jaundice, diabetes, and pancreatitis. [1, 2] Risk for PaCa dramatically increases with age. Two-thirds of the PaCa patients are 65 years of age or older, with an average age at diagnosis of 71 years. [3] With debilitating symptoms, higher risk at older age, and associated clinical manifestations, PaCa is often associated with increased morbidity, poor prognosis, high mortality rates, and decreased health-related quality of life (HRQOL).

Clinical symptoms in a majority of patients with pancreatic cancer (PwPC) become visible at the metastatic stage. [4] Due to diagnosis at later stages, more than 85% of PwPC are not suitable candidates for surgical resection and require palliative treatment. This primarily involves chemotherapy, radiation, immunotherapy, and chemoradiation. [5] Presently, palliative treatments improve overall survival marginally, while treatment-related toxicities further add to the symptom profile. [6] Due to

minimal prolongation of overall survival, a broad symptom profile, and a high mortality rate, a patient's HRQOL becomes of paramount importance. Further evidence suggests an association between higher HRQOL and better overall survival in PwPC. [7–9]

Patient's willingness and ability to manage their health independently has a positive association with HRQOL. Understanding one's disease condition and possessing the knowledge, skills, and confidence to manage one's health makes patients activated and engaged members of the health care team. [10] Highly activated patients have reported better health outcomes and higher HRQOL scores. [11] In 2004, Hibbard et al. described the development of a 13-item patient activation measure (PAM). PAM is a valid, reliable, unidimensional, probabilistic, and Guttman-like scoring scale. [11] [12] Based on the patient's score on PAM, they can be classified into four-varying levels of patient activation. [12–14] At level 1, patients are least activated while those at level 4 are most activated in terms of confidence, skills and knowledge at managing their own health.

Studies among chronically ill patients highlight that those with higher PAM scores had better patient outcomes such as quality of life, physical and mental functional status, and patient satisfaction. [11, 15] Further, patients with higher activation scores have lower healthcare resource utilization, better patient-care experience, [16] and higher HRQOL. [15] Similarly, for cancer patients, higher patient activation scores or levels were associated with better care coordination with the health team, [17] greater decision control, [18] a higher likelihood of following a healthier lifestyle, and a higher likelihood of communicating health concerns and following health-care providers recommendations. [19] Regarding HRQOL among cancer patients, positive trends of association were observed between HRQOL scores and PAM scores or patient activation levels for multiple cancer types. [20, 21]

Pancreatic cancer's poor prognosis, high mortality rate, higher prevalence among the elderly, and minimal survival prolongation with current treatments highlight the importance of patients' HRQOL. Increasingly, evidence among other cancers suggests an association between patient activation and HRQOL. [15, 20–22] This study aimed to evaluate patient activation and HRQOL of PwPC and the relationship between the two constructs while controlling for covariates.

Methods

Study Design

This study employed a non-experimental, cross-sectional survey design. A self-reported questionnaire collected data from locally advanced or stage IV or recurrent PwPC selected through convenience sampling. Locally advanced, stage IV and recurrent PwPC were considered a target population of this study as they frequently visited clinics for chemotherapy treatment. The patient completed surveys during their visits. The survey instrument consisted of questions measuring patient activation, HRQOL, demographics and clinical factors. We collaborated with Texas Oncology clinics in Texas for data collection, where patients were recruited at 11 care sites with significant populations of PwPC. Texas

Oncology participates in the oncology care model (OCM), and participating clinics are within the more extensive network of 210 clinics across Texas and Oklahoma. The OCM is a program initiated by the Centers for Medicare and Medicaid Services (CMS) that focuses on high-quality patient care, treatment experience, and management of side effects, with a goal of reducing hospital and emergency room visits. [23]

Measures

The 38-item, paper-based survey was subdivided into three sections. Section 1 consisted of the Patient Activation Measure – 13 items (PAM-13), section 2 was the functional assessment of cancer therapy – Hepatobiliary Cancer Symptom Index – 18 items (FHSI-18), and section 3 consisted of 12 items that included measures of patient demographics and disease characteristics.

Patient activation was measured using the PAM-13, an interval level, unidimensional, Guttman-like measure developed using Rasch's methodology. [12] Patient responses are scored on a scale of 0-100, where higher scores indicate higher patient activation. Based on total scores, patients can be divided into four levels. These levels of activation follow a hierarchical order. In the first level, patients realize the importance of self-management of their health. Patients in the second level are aware of their medication and required lifestyle changes but believe that health is not in their control. Patients at this level are able to set simple goals. The third level stage involves taking action, such as maintaining a lifestyle and handling problems and symptoms. In the fourth level, patients remain activated under the stress of their daily routine or any change in the status quo of their ailment. [12, 13] In this study, patients at lower activation levels (1 &2) are collapsed together as "low patient activation".

The HRQOL in pancreatic cancer patients was measured using the 18-item version of the FACT-Hep tool, named FHSI-18. The shorter FHSI-18 version was derived from the FACT-HEP. The FHSI-18 is rated on a range of 0–72, with four subscales: Disease-Related Symptoms- Physical (FHSI-DRS-P-12) scale with a range of 0–48, Disease-Related Symptoms- Emotional (FHS-DRS-E-2) scale with a range of 0–8, Functional Well-being (FHSI-FWB-3) scale with a range of 0–12, and Treatment Side Effects (FHSI-TSE-1) scale with a range of 0–4. Each item on the scale is rated on a 5-point Likert type scale, with 0 referring to "Not at All" to 4 referring to "Very Much." Patients with higher scores reflect better symptom control and a higher quality of life. In previous psychometric properties assessments, the scale had reported high internal consistency and statistically significant convergent & discriminant validity.[24]

Patients' demographics and clinical characteristics information were collected using single-item measures. Variables included: age, race/ethnicity, gender, education level, family history of pancreatic cancer, household income, insurance status, marital status, time since cancer diagnosis, tumor stage at diagnosis, treatment history, and co-morbidities.

Study Sample and Sample Selection

The study population consisted of patients from 11 Texas Oncology clinics in Texas. Patients eligible for study met the following inclusion criteria: (1) Adults (18 years or older) receiving care at the study clinic site, (2) Able to read and write in English, (3) Diagnosed with locally advanced (unresectable), stage IV or recurrent pancreatic cancer, (4) Being treated with first-line or second-line chemotherapy, and (5) Expressed willingness and consent to participate. Patients meeting the inclusion criteria were enrolled on a continuous basis via convenience sampling by the clinical research staff during their routine clinic visit. The clinical research staff were trained on patient recruitment procedures before the beginning of enrollment. The clinical research staff screened patients as per the inclusion/exclusion criteria, and those who qualified were recruited in the study. The study cover letter, along with the survey, included information on the purpose of the study, voluntary nature of study participation, the importance of the respondents' participation, the approximate time to complete the study, assurance of confidentiality of responses as well as the contact information of the primary investigator and the University's IRB. The patients who were approached but did not consent to enroll were logged in by research staff to monitor the patient response rate. Patients who expressed willingness to participate in the study received a cover letter describing the study and a self-reported survey to complete. No patient health information (PHI) or other electronic health record (EHR) data were accessed or used during this study.

Data Analyses

The data analyses were conducted using R Studio version 1.1.463. The a priori level of significance for all statistical comparisons was set at $p < 0.05$. Responses were analyzed with both descriptive and inferential statistics. Descriptive statistics included means, standard deviation, frequencies, and percentages. T-test and analysis of variance (ANOVA) tests were conducted to assess the differences in means for all variables. Chi-square tests/fisher's exact test were used to assess the association between categorical variables. Multiple linear regression was used to predict the effect of patient activation score/levels on the patients' total and domain HRQOL scores. Assumptions of normality and homoscedasticity were also assessed.

Results

Sample Characteristics

Fifty-six (n = 56) PwPC completed the survey, out of sixty-one eligible patients that were approached to participate (response rate of 91%). The average age was 69.5 ± 11.1 years, the majority of patients were females (51.8%) and either married or living with a partner (66.1%). Most patients were Caucasian (61.8%), had a college degree or higher (59%), had private insurance (36.4%), and had an annual household income of more than $50,000 (61.2%). In terms of clinical factors, most patients were diagnosed at stage 4 (48.2%), within the last three months (46.4%) and had no family history of the disease (83.6%). Patient demographics are described in Table 1.

Table 1
Demographic and Clinical Characteristics of Study Participants

Variable	Mean (SD)
Age (n = 53) [α]	69.5(11.1)
Number of comorbidities (N = 56)	3.2 (1.8)
	Frequency (%)
Gender (n = 56)	
Male	27 (48.2%)
Female	29 (51.8%)
Race/Ethnicity (n = 55) [α]	
African American or non-Hispanic black	13 (23.6%)
Caucasian or non-Hispanic white	34 (61.8%)
Other	8 (14.5%)
Asian-American or Pacific Islander	2 (3.6%)
Mexican American or Hispanic	6 (10.9%)
Native Americans	0 (0.0%)
Education Level (n = 56)	
Less than high school/ High school graduate	23 (41.1%)
College graduate	23 (41.1%)
Postgraduate	10 (17.9%)
Household Income (n = 54) [α]	
Less than $25,000	13 (24.1%)
$25,000–50,000	8 (14.8%)
$50,000–75,000	9 (16.7%)
$75,000-100,000	11 (20.4%)
Greater than $100,000	13 (24.1%)
Health Insurance Status (n = 55) [α]	
Public Insurance Only (Medicare/ Medicaid/ Tricare)	19 (34.5%)

*: Percentage exceeding 100% α: Frequency lower than N = 56, due to missingness

Variable	Mean (SD)
Private Insurance Only	20 (36.4%)
Multiple	16 (30.9%)
Marital Status (n = 56)	
Married/ Living with Partner	37 (66.1%)
Single, in a relationship	1 (1.8%)
Married	34 (60.7%)
Partner/Living Together	2 (3.6%)
Not Married/ Living with Partner	19 (33.9%)
Widowed	9 (16.1%)
Divorced or separated	2 (3.6%)
Single, never married	8 (14.3%)
History of Pancreatic Cancer in Immediate Family (n = 55) [α]	
Yes	8 (14.5%)
No	46 (83.6%)
Time since Initial Pancreatic Diagnosis (n = 54) [α]	
Less than 3 months	26 (46.4%)
3 months to 1 year ago	15 (26.8%)
More than 1 year ago	13 (23.6%)
Stage of Pancreatic Cancer at the Time of Initial Diagnosis (n = 55) [α]	
Stage 1 or 2	9 (16.1%)
Stage 3	11 (19.6%)
Stage 4	27 (48.2%)
Not Sure	9 (16.1%)
Description of Treatment History (n = 56)	
Newly Diagnosed	37 (66.1%)
Prior Treatment History	19 (33.9%)

*: Percentage exceeding 100% α: Frequency lower than N = 56, due to missingness

Variable	Mean (SD)
Number of Comorbidities (n = 56)	
0	9 (16.1%)
1	17 (30.4%)
2	14 (25%)
3	5 (8.9%)
4	5 (8.9%)
5 +	6 (10.7%)
Comorbidity Type (n = 56) *	
HTN	27 (48.2%)
Diabetes	18 (32.1%)
Arthritis	14 (25.0%)
Hypercholesterolemia	16 (28.5%)
Anxiety	9 (16.0%)
Depression	8 (14.2%)
Pancreatitis	5 (8.9%)
Kidney Problem	6 (10.7%)
Heart Disease	5 (8.9%)
Asthma	3 (5.3%)
Other	4 (9.5%)
*: Percentage exceeding 100% α: Frequency lower than N = 56, due to missingness	

Patient Activation

Mean patient activation score was relatively high (mean PAM score: 63.5 ± 17.2; range: 0-100) with most patients (70.2%, n = 39) at higher patient activation levels (levels 3 or 4) as seen in Table 2. Patient activation score was significantly higher among those that were married or partnered (68.1 ± 15.0) compared to those that were single, divorced or not partnered (54.5 ± 18.0). Patients with public insurance only reported significantly lower PAM scores (53.4 ± 17.1) versus those with private insurance only (66.8 ± 14.2) or multiple insurances (72.3 ± 15.4). Similar significant bivariate relationships were observed for PAM levels. A significantly higher number of patients that were married or partnered were at higher PAM levels, i.e., level 3 or 4. Those with private insurance only or multiple insurances were at higher PAM

levels. The Cronbach's coefficient for PAM was 0.94, indicating high internal consistency in the study sample for the measure.

Table 2
Patient Activation Level Distribution (N = 56)

Patient Activation Level	Frequency (%)
Level 1	6 (10.7%)
Level 2	11 (19.6%)
Level 3	23 (41.1%)
Level 4	16 (28.6%)

Health-Related Quality of Life

The mean HRQOL score was low, 40.9 ± 12.6 (range: 12-66.7) when assessed using FHSI-18. The average domain-specific scores were Disease-Related Symptoms – Physical (FHSI-DRS-P) 27.7 ± 9.4 (range: 8-44.7), Disease-Related Symptoms – Emotional (FHSI-DRS-E) 4.3 ± 2.2 (range: 0–8), Treatment Side Effects (FHSI-TSE) 2.6 ± 1.2 (range: 0–4), and Functional Well-being (FHSI-FWB) 6.2 ± 3.3 (range: 0–12). The overall Cronbach's alpha for FHSI-18 was 0.87, indicating high internal consistency. The internal consistency values for the FHSI domain scales were also high (Table 3).

Table 3
FHSI-18 scores (N = 56)

FHSI-18 Domain	Mean (SD)	Range	Reliability
FHSI-DRS-P (Disease Related Symptoms-Physical)	27.69 (9.4)	8-44.7	0.84
FHSI-DRS-E (Disease Related Symptoms-Emotional)	4.30 (2.2)	0–8	0.76
FHSI-TSE (Treatment Side Effects)	2.58 (1.1)	0–4	N/A*
FHSI-F/WB (Function/Well-Being)	6.16 (3.4)	0–12	0.86
FHSI-18 Total	40.96 (12.67)	12-66.7	0.87

*Single item in the domain. Reliability not assessed. *Abbreviations*– FHSI–18: Functional Assessment of Cancer Therapy Hepatobiliary Cancer Symptom Index– 18 item version; FHSI DRS–P: FHSI–Disease Related Symptoms–Physical; FHSI–DRS–E: FHSI–Disease Related Symptoms– Emotional; FHSI–TSE: FHSI– Treatment Side Effects; FHSI–F/WB: FHSI– Functional Well Being

Bivariate analyses for total HRQOL scores and demographic/clinical variables showed no significant relationships. However, significant bivariate relationships were observed for specific domains: HRQOL-physical (FHSI-P), HRQOL-emotional (FHSI-DRS-E), HRQOL- functional wellbeing (FHSI-FWB), and HRQOL-treatment side effects (FHSI-TSE) and clinical/demographic variables. Males (4.96 ± 2.13) had significantly higher scores for HRQOL-emotional compared to females (3.68 ± 2.12). Patients with college degrees reported significantly lower HRQOL-emotional scores. Increasing age was significantly correlated

with higher HRQOL-treatment side effects (Cor = 0.29, $p < .05$) and HRQOL-physical (Cor = 0.27, $p < .05$) scores.

Multivariate Analyses

Multiple regression analysis was conducted to examine the predictive ability of PAM levels in explaining overall HRQOL and domain scores. Only the covariates (age, education, and gender) that had significant bivariate associations with overall HRQOL or domains were added to the model to achieve a parsimonious model.

Overall HRQOL

Patients at activation level 4 had significantly higher overall HRQOL score when compared to those lower activation level (level 1 or 2) while controlling for age, education, and gender. The overall model was significant and accounted for 21% of the variation in total HRQOL (F-statistic: 2.23, 6 and 49 DF, $p < .05$) (Table 4).

Table 4
Regression of HRQOL with PAM levels (low, 3 and 4) while controlling for Age, Gender, and Education Levels

Variables	Estimate	Std. Error	T- Value	P- Values
Intercept	28.09	11.09	2.53	**0.014***
Independent Variable				
PAM Level 3^	3.59	4.12	0.87	0.38
PAM Level 4^	12.88	4.32	2.98	**0.00445 ***
Covariates				
Age	0.13	0.15	0.86	0.39
Education Level				
College Graduate$	-5.25	3.74	-1.40	0.16
Post-Graduate$	-1.12	4.68	-0.24	0.81
Gender				
Femaleμ	1.84	3.30	0.56	0.57
Multiple R−squared: 0.21, Adjusted R−squared: 0.11				
F−statistic: 2.23 on 6 and 49 DF, p−value<0.05*				
Dependent Variable = Health−Related Quality of Life				
*: Statistical Significance at p <0.05; ^: reference variable is PAM level 1 or 2; $: reference variable is less than high school/high school graduate; μ: reference variable is male				
Abbreviations−PAM: Patient Activation Measure				

HRQOL-Physical (FHSI-P)

Patient activation was not significantly associated with HRQOL-Physical score, controlling for age; however, the overall model was significant and explained 14% of the variation in HRQOL-physical (F statistic: 2.82, 3 and 49 DF, p = 0.048) (Table 5).

Table 5
Multiple Regression Analysis of Health-Related Quality of Life-Physical (FHSI-DRS-P) with Patient Activation Levels (low, 3 and 4)

Variables	Estimate	Std. Error	T- Value	P- Values
Intercept	11.53	8.15	1.41	0.16
Independent Variable				
PAM Level 3^	0.78	2.89	0.27	0.78
PAM Level 4^	6.18	3.24	1.90	0.06
Covariates				
Age	0.19	0.11	1.74	0.08
F = 2.82, df =3 and 49, p = 0.048*, Multiple R2 = 0.14, and Adjusted R2 = 0 .09				
Dependent Variable = Health–Related Quality of Life– Physical (FHSI–DRS–P)				
*: Statistical Significance at p <0.05; ^: reference variable is PAM level 1 or 2				

HRQOL-Emotional (FHSI-E)

Patient at activation level 4 had significant higher HRQOL-Emotional score when compared to those at lower activation levels (level 1 or 2). Also, those that were college graduates or postgraduates had significantly lower HRQOL-emotional score than those that studied up until high school. The overall model was significant and explained 24% of the variation in HRQOL-emotional (F statistic: 3.26 on 5 and 50 DF, p = 0.012*) (Table 6).

Table 6
Multiple Regression Analysis of Health-Related Quality of Life- Emotional (FHSI-DRS-E) with Patient Activation Levels (low, 3 and 4)

Variables	Estimate	Std. Error	T- Value	P- Values
Intercept	3.64	1.10	3.28	0.00096*
Independent Variable				
PAM Level 3^	0.77	0.69	1.11	0.27
PAM Level 4^	1.47	0.72	2.04	0.0467 *
Covariates				
Gender				
Female μ	-1.02	0.55	-1.86	0.06
Education Level				
College Graduate $	-1.65	0.62	-2.63	0.0111 *
Postgraduate $	-1.69	0.78	-2.14	0.0370 *
F = 3.26, df =5 and 50, p = 0.012*, Multiple R2 = 0.24, and Adjusted R2 = 0 .17				
Dependent Variable = Health–Related Quality of Life– Emotional (FHSI–DRS–E)				
*: Statistical Significance at p <0.05; ^: reference variable is PAM level 1 or 2; $: reference variable is less than high school/high school graduate; μ: reference variable is male				

HRQOL-Treatment Side Effects (FHSI-TSE)

Patient activation was not a significant predictor of HRQOL-Treatment side effect scores, while age ($p < 0.05$) was a significant positive predictor. The overall model was not significant (F statistics: 1.62 on 3 and 49 DF, $p = 0.19$). (Table 7)

Table 7
Multiple Regression Analysis of Health-Related Quality of Life-Treatment Side Effects (FHSI-TSE) with Patient Activation Levels (low, 3 and 4)

Variables	Estimate	Std. Error	T- Value	P- Values
Intercept	0.47	1.00	0.46	0.64
Independent Variable				
PAM Level 3^	0.21	0.35	0.60	0.54
PAM Level 4^	0.21	3.24	0.54	0.59
Covariates				
Age	0.02	0.01	2.09	0.0418 *
F = 1.62, df =3 and 49, p = 0.19, Multiple R2 = 0.09, and Adjusted R2 = 0.03				
Dependent Variable = Health–Related Quality of Life– Treatment Side Effects (FHSI–TSE)				
*: Statistical Significance at p <0.05; ^: reference variable is PAM level 1 or 2				

HRQOL-Functional Well Being (FHSI-FWB)

Patients at activation level 4 ($p < .01$) or being a female ($p < .05$) had significantly better HRQOL-Functional Wellbeing score when compared to those that are either at lower activation levels (level 1 or 2) or males. The overall model was significant and explained 24% of the variation in HRQOL-functional wellbeing (F statistic: 5.64 on 3and 52 DF, $p = 0.0020$*). (Table 8)

Table 8
Multiple Regression Analysis of Health-Related Quality of Life- Functional Well Being (FHSI-FWB) with Patient Activation Levels (low, 3 and 4)

Variables	Estimate	Std. Error	T- Value	P- Values
Intercept	3.46	0.91	3.79	0.00039*
Independent Variable				
PAM Level 3^	1.44	0.99	1.46	0.15
PAM Level 4^	3.71	1.06	3.48	0.0010*
Covariates				
Gender				
Female µ	2.01	0.82	2.43	0.0184*
F = 5.64, df = 3and 52, p = 0.0020*, Multiple R2 = 0.24, and Adjusted R2 = 0.20				
Dependent Variable = Health–Related Quality of Life– Functional Well Being (FHSI–FWB)				
*: Statistical Significance at p <0.05; ^: reference variable is PAM level 1 or 2; $: reference variable is less than high school/high school graduate; µ: reference variable is male				

Discussion

Studies evaluating patient activation have reported that higher activation levels are associated with better clinical and HRQOL outcomes. [25] In several cancer conditions, patients at lower activation levels were poor managers of their health and experienced poor HRQOL. [15, 18, 26] Considering the debilitating nature of PaCa, improving the HRQOL of patients is of pivotal importance. This study aimed at understanding the role of patient activation in predicting HRQOL in PwPC.

In this study, the mean patient activation score was relatively high, with more than half of patients at either at level 3 or 4 of activation. Patient activation was predictive of overall HRQOL as well as HRQOL domains. Overall, the model explained 21% variation in HRQOL with being at higher activation (level 4) as a significant positive predictor of HRQOL, controlling for age, gender, and education. In terms of HRQOL domains, being at patient activation level 4 was significant predictor of emotional and functional well-being domains when adjusted for demographic covariates. These findings are corroborated by studies among patients with other types of cancers. In a study among Swedish patients diagnosed with either upper gastrointestinal, gynecological, hematological, or head & neck cancers patients at higher activation level had significantly higher global, social and functional domain HRQOL scores when compared to those as lower activation levels. [21] A study by Jansen et al. among patients who had undergone laryngectomy found a significant positive correlation between patient activation and HRQOL. [22] Positive associations between patient activation and HRQOL were also observed in patients with breast cancer.

[15, 20] In a study of patients with breast cancer, patient activation was significantly related to HRQOL, while controlling for cancer literacy level, the number of treatment types received, and education level. [20] Moreover, these findings are consistent with extant literature examining HRQOL in other conditions. For example, Yadav et al. reported that higher patient activation and self-management led to better QOL outcomes among chronic obstructive pulmonary disease patients. [27] Similar results were also reported among chronic kidney disease patients, where patient activation was strongly associated with HRQOL. [28] Thus, improving patient activation through interventions can lead to enhancement in both domain specific and overall HRQOL of PwPC. The implications of these results become even more pronounced in those that are diagnosed at later stages or are patients with recurrent PaCa.

Patient activation varied based on demographic characteristics. Activation was specifically lower for patients with public health insurance when compared to those with private or multiple insurances. It has been reported in previous studies that patients with private insurance frequently purchase the insurance through an employer. While those that qualify for public health insurance are often unemployed or have a low paying job or work part-time. [29] Patients that are employed have more confidence to manage their health conditions and are more highly activated due to financial security provided through jobs. [17] Even though all the sites in this study were high functioning i.e., they participated in Oncology Care Model (OCM) and other value-based care models, patients with low socioeconomic status (SES) demonstrated low patient activation. Evolving health care delivery and payor systems enable identification of patients at lower SES. Prior identification of these patients is important as the opportunity to improve patient activation is much higher. Patient activation scores were significantly higher for patients who were married/living with a partner than those who were divorced/separated/widowed. [17, 25, 30] This evidence is in line with other studies and is attributed to a wider social network, [31, 32] constant support, better economic safety net, [32] and ability to manage health conditions among those that are partnered. [33, 34] Patients that are at lower SES and/or not partnered can be specifically identified for enhanced services to improve self-management. These services can involve promoting patient-provider communication, working on patient's question-asking skills, and imparting patient-focused communication training to oncologists. [11, 35, 36]

With the high prevalence of PaCa among older adults, minimal prolongation of overall survival with current treatment modalities, and high disease mortality rates, interventions to improve patient activation levels should be implemented. Improvement in knowledge, skills, and confidence will lead to patients being involved in their health and potentially experiencing a higher HRQOL. Multiple programs aiming at improving patient activation have been extensively studied for other cancers and disease conditions. In addition to increase in HRQOL, interventions aimed at improving patient activation led to better dietary and exercise habits, improved patient's providers perception and reduced anxiety and stress among patients suffering with prostate cancer. [37] In another study among breast cancer patients, the Nurse Case Management program included assigning a dedicated nurse or health worker as an educator enhanced patient's perception of provider's role and increased confidence to adapt to challenges that arise during the treatment. [38] Similarly, the telephone-based-care coordination or CONNECT program conducted among older adults with colorectal cancer over six months also decreased stress and

improved psychological QOL. [39]. Therefore, interventions targeted at enhancing patient activation may lead to improvement not only in HRQOL but other positive health behaviors too.

Limitations

The data collected in this study was self-reported by the study participants. Therefore, data is prone to self-reporting biases (social desirability and recall bias). A second limitation arises due to the method of recruiting patients. The study employed convenience sampling, which may result in selection bias. There is a possibility that the participants that agreed to complete the survey were more activated and were inclined to participate in the study.

Third, due to the study's cross-sectional nature and the sample size, the results were descriptive rather than inferential. Hence, the causality of the relationships could not be inferred. A final limitation is that all participating sites were from the Texas Oncology group. Therefore, the findings might not represent the pancreatic cancer patient population in the state of Texas or the US. Relatedly, the sites implement OCM to improve the patient care experience; therefore, the findings may be more representative of individuals treated in clinical sites that implement similar value-based care models. Also, the patient sample was limited as it included only those suffering from late stage or recurrent PaCa.

Suggestions For Future Research

Future research could consider conducting randomized control trials (RCT) that assess the impact of behavioral interventions on improving patient activation levels. The interventions for improving patient activation could be designed to specifically target vulnerable populations (low SES, not partnered, and lower education levels). Also, there is a lack of research on patient activation and HRQOL in patients with a less prevalent form of neuroendocrine pancreatic cancer. However, sample size could be an issue with this patient population.

Conclusion

This study aimed to understand the association between patient activation and HRQOL of patients with pancreatic cancer. The results indicate that patient activation is a significant positive predictor of HRQOL of late stage or recurrent PwPC while controlling for covariates. Efforts should be made to design interventions that target patient activation, thereby improving overall and domain specific HRQOL outcomes. Also, measures may be required to bolster patient activation among patients who are poor and/or have social support deficiencies. Research amongst a larger sample and more diverse pancreatic cancer population is required for conclusive evidence.

Declarations

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Competing Interests

The authors declare no competing interests.

Author Contributions

All authors contributed substantially to the design and conduct of the study.

Ethics Approval

The study was approved by the University of Texas at Austin Institutional Review Board (#2018-09-0042).

Consent to participate

Informed consent was obtained from all individuals participating in the study.

Consent to publish

Not applicable

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