Short communication

Does patient activation level affect the cancer patient journey?

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A B S T R A C T

Objectives: We assess how patient activation is associated with behaviors and experiences of people with cancer, including: understanding risks; making treatment decisions; communicating with providers; coping with symptoms; and adhering to regimens.
Methods: The study utilizes survey data from six surveys each including 500 cancer survivors. Multivariate analyses are presented.
Results: Higher activated patients are more than 9 times more likely to feel their treatment plans reflect their values, 4.5 times more likely to cope with side effects, and almost 3.3 times more likely to initiate a healthier diet after their diagnosis, than are less activated patients. Less activated patients are less likely understand their diagnosis, to follow treatment regimens, and to be satisfied with their care.
Conclusions: The findings show that all along the care continuum, patient activation is associated with differences in experiences.
Practice implications: The findings point to the value of assessing patients' activation levels at the beginning of their cancer experience.

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1. Introduction

Patient activation is defined as the individual's knowledge, skill, and confidence for managing their own health [1,2]. There is growing evidence about the importance of patient activation in supporting positive outcomes among chronic disease patients [3,4]. More activated patients are more likely to adhere to treatment regimens, to monitor conditions, to obtain recommended care, and to have better clinical outcomes [5–9]. While this evidence comes from a variety of settings and within patient populations, there are only a few studies that focus on patient activation in cancer patients. The studies that do tend to examine only one type of cancer [10–13]. Studies that take a broader view show that patient activation is linked with attitudes toward cancer, satisfaction with care, and the likelihood of getting a cancer screening [14–16].

As more patients survive cancer, they need to self-manage on a long term basis. Cancer as a chronic illness places new demands on patients to manage their own care, often with minimal clinical advice or supervision. Chronic cancer care is often delivered in brief ambulatory clinical encounters, and patients and their families increasingly take on responsibility for day-to-day management of their illness [17]. This includes management of symptoms, adhering to complex treatment regimens, as well as adopting new behaviors to reduce the risk of recurrence of their disease.

Using survey data from cancer patients, we assess how patient activation level is associated with the adoption of behaviors, symptom management, communication with providers, and satisfaction related to cancer care across a broad range of cancers.

2. Methods

2.1. Design

The study utilizes survey data collected by CancerCare®, who fielded six different on-line surveys among cancer patients [18]. Each survey contained no more than 41 questions including the patient activation measure (PAM) and demographics. To minimize respondent burden, respondents were randomly assigned to receive one of the surveys. Each survey focused on experiences and patient behaviors relating to different phases of the cancer experience.

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2.2. Study sample

For each survey, cancer patients were recruited through consumer panels. The convenience samples were limited to those 25 years or older who had received a diagnosis of cancer. Fifty percent of each survey sample includes common cancers (lung, breast, colorectal, and prostate). For each survey, 3000 unique participants were invited by email, and approximately 500 responded to each survey.

2.3. Variables

Activation was measured using the Patient Activation Measure (PAM) [1]. Created with Rasch analysis, the PAM is a latent construct, assessing an individual's self-concept as a manager of their health. PAM items include statements about confidence, beliefs, knowledge, and skills (e.g. "I know how to prevent problems with my health," "I am confident that I can tell a doctor my concerns, even when he or she does not ask."). Patients are categorized into four levels of activation which have been previously validated, representing progression from a passive care recipient (level one) to patients who are more proactive in managing their health (level four) [1,2]. Because of smaller numbers in these lower levels, levels 1 and 2 are collapsed in the analysis.

2.3.1. Indices

Four indices were created using a varimax rotated factor analysis. Items with factor loadings of at least .5 were retained for the index.

Understanding my cancer diagnosis: How easy was it to . . .
Understand the kind of cancer I had
Understand the stage of cancer I had
Understand my diagnosis
How to find the best cancer treatment for me
Quality-of-life issues related to living with cancer
Where to find more information about my cancer"Very Hard" (1) to "Very Easy" (5) (range 6–30)*Follows doctor recommendations*: How often you follow your doctor's recommendations on: Diet; Exercise; Sleep?

Never; Rarely; Sometimes; Often; Always. (range 3–15)*Reporting symptoms and side effects*: How often did you:Discuss my symptoms/side effects with my doctor

Discuss my symptoms/side effects with a nurseNever; Rarely; Sometimes; Usually; Always. (range 2–10)*Satisfaction with care*: How satisfied are you with your cancer care, in terms of:The impact on your activities of daily living

The side effects of the treatments
The symptoms you experience
How you feel physically, day to dayVery Dissatisfied (1) to Very Satisfied (5) (range 4–20)Other outcome variables were single survey items focusing on; behaviors; treatment planning; managing symptoms, and adherence.

3. Results

Table 1 shows the characteristics of the study population. Over half the study sample is female (57%), and sixty-eight percent are 55 years or older. Thirty-two percent of the study participants have incomes lower than $50,000. Fifty-two percent have less than a college education, and 68% are white. The study population is evenly distributed across the regions of the country, and 39% had their cancer diagnosed within the two years before the survey.

The multivariate analysis results (Table 2), indicate that after controlling for demographics and health status factors, higher activated patients are 4.7 times more likely to have begun to

Table 1
Study population characteristics.[a]

Gender	Percent
Male	43%
Age	
25–34	9
35–44	11
45–54	13
55–64	29
65–74	30
75+	9
Income	
<25k	12
25 to <35k	8
35 to <50k	12
50 to <75k	19
75 to <100k	17
100 to<150k	16
150+k	8
Education	
High school or less	15
Some college	24
Associate degree	13
Bachelor's degree	28
Graduate degree	17
Ethnicity	
White	68
African American	16
Hispanic	8
Asian	3
Other	5
Geographic region	
Midwest	24
Southwest/West	26
Southeast	26
Northeast	24
Time since diagnosis	
Last 12 months	18
13 months to 2 years	21
2–4 years	19
Over 4 years	41

[a] From survey 1.

exercise and 3.3 times more likely to have begun to eat a healthier diet after diagnosis as compared to less activated patients. More activated patients were 10% more likely to voice concerns or make suggestions in the treatment planning process as compared to less activated patients. More activated patients were 9.5 times more likely to indicate that the treatment plan reflected their values and goals than those less activated. Higher activated patients were 3.2 times more likely to feel they had sufficient information regarding treatment risks, 4.5 times more likely to effectively manage side effects, and 45% more likely to take medications as directed, as compared to less activated patients.

The adjusted mean scores of the indices in Table 3 indicate that less activated patients have a 13% lower score on the index assessing understanding of their cancer diagnosis, as compared to higher activated patients (Anova 4.6, $p < .000$). Less activated patients have a 27% lower score on the index regarding following doctor's recommendations as compared to higher activated patients. There is a 28% differential between the higher and lower activated patients on the index on discussing side effects. Similarly, there is a 33% differential on the satisfaction index. Higher activated patients are significantly more satisfied with their care.

4. Discussion and conclusions

4.1. Discussion

All long the continuum of care, more activated patients are likely to be better informed and more proactive about managing

Table 2
Odds ratios associated with experiences and behaviors of cancer patients by activation level.

	PAM Level 1 and 2 Odds Ratio	PAM Level 3 Odds Ratio	PAM Level 4 Odds Ratio
After diagnosis behavior – within 2 months ($n = 441$)			
Exercised more	1.0 (reference)	2.2 ($p = .05$)	4.7 ($p = .00$)
Eat healthier diet	1.0 (reference)	1.56 ($p = .24$)	3.3 ($p = .00$)
Treatment planning ($n = 531$)			
Treatment plan reflects my values and goals	1.0 (reference)	4.7 ($p = .00$)	9.5 ($p = .00$)
I was given a written treatment plan	1.0 (reference)	2.0 ($p = .11$)	4.4 ($p = .00$)
I had enough info when deciding on treatment: Risks	1.0 (reference)	2.0 ($p = .05$)	3.2 ($p = .00$)
Impacts on my activities	1.0 (reference)	1.6 ($p = .18$)	2.7 ($p = .01$)
I voiced my concerns during treatment planning	1.0 (reference)	.177 ($p = .64$)	1.1 ($p = .01$)
I made suggestions	1.0 (reference)	.17 ($p = .75$)	1.1 ($p = .05$)
Managing side effects and symptoms of treatment ($n = 476$)			
Able to control side effects of treatment – Mostly or completely	1.0 (reference)	2.37 ($p = .01$)	4.49 ($p = .00$)
Down play symptoms – b/c I don't want to bother the doctor	1.0 (reference)	.58 ($p = .08$)	.30 ($p = .00$)
Adherence to medications			
Take RX medications as directed	1.0 (reference)	1.14 ($p = .02$)	1.45 ($p = .00$)

Logistic regression models control for age, gender, ethnicity, education, income, time since cancer diagnosis and number of chronic conditions.

Table 3
Adjusted mean scores on indices of behavior and experiences of cancer patients by PAM level.

	PAM level 1 and 2	PAM level 3	PAM level 4	ANOVA	df
Understand My Cancer Diagnosis, 6 items (range 6–30), $n = 342$	22.3***	23.7***	25.1***	4.6	2
Follow Doctors Recommendations, 3 items (range 3–15), $n = 500$	5.6***	6.2***	7.1***	6.4	2
Discuss side effects and symptoms with care team (range 2–10), $n = 449$	5.3***	6.2***	6.8***	10.4	2
Satisfaction with the impact of care, 4 items (range 4–20), $n = 442$	12.8***	16.1***	17.0***	18.7	2

Multivariate models control for age, gender, ethnicity, education, income, time since cancer diagnosis and number of chronic conditions.
  *** $p < .000$.

their condition. They are more likely to understand their diagnosis, feel sufficiently informed about their treatment plan and believe that these plans reflect their values. Higher activated patients are more likely to report being able to effectively manage symptoms/ side effects.

The findings are similar to what has been found in assessing patient activation within other chronic diseases as well as those focusing on cancer [6]. And while there have been other studies that have investigated the relationship between patient activation and cancer experience, this is the first study that examines multiple behaviors and experiences across a broad range of types of cancers.

The convenience sample is a limitation of the study, and although efforts were made to make the sample representative, it is difficult to say with certainty how closely the sample represents the larger population of cancer patients. Further the cross-sectional nature of the data means that it is not possible to determine the time ordering of events or to determine causality. Future studies should focus on longitudinal samples to observe the time ordering of events and assess how changes in activation relate to changes in behaviors and outcomes.

4.2. Conclusions

The findings give insight into how activation level may influence the cancer patient journey, with less activated patients less likely to communicate concerns to their providers, less likely to adopt healthy lifestyle behaviors, more likely to be ill informed about their cancer, less likely to be able to manage symptoms, and less likely to follow their doctors recommendations.

4.3. Practice implications

Together these results highlight how vulnerable less activated patients are to poor care experiences and possibly poor outcomes.

The findings point to the value of assessing patient activation levels at the beginning of the cancer experience, and similarly to other chronic conditions [4], providing more support to less activated patients.

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Conflicts of interest

Judith Hibbard and Eldon Mahoney are consultants to and equity stakeholders in Insignia Health. Ellen Soney has no potential conflicts of interest to report.

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