


BRIEF REPORT OPEN ACCESS

Patient Activation and Shared Decision-Making Among Hispanics/Latinos With Metastatic Cancer: A Qualitative Study

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ABSTRACT

Background: Patient activation is established when patients are equipped with the necessary knowledge, skills, and motivation to meaningfully participate in managing their health and, along with shared decision-making, improves clinical outcomes like treatment adherence. Little is known regarding patient activation among Hispanics/Latinos with metastatic cancer, who report worse quality of life and symptom burden compared to non-Hispanic/Latino Whites.

Aims: This study aimed to characterize barriers and facilitators to patient activation and shared decision-making among English- and Spanish-speaking Hispanics/Latinos with metastatic cancer.

Methods: Three, 2-h focus groups with Hispanics/Latinos with metastatic solid tumors ($N = 22$) were audio-recorded and transcribed. Semi-structured interviews addressed experiences living with metastatic cancer, palliative care beliefs, and communication with healthcare team. Barriers and facilitators were identified through secondary analysis of interviews.

Results: Barriers included: (a) feeling overwhelmed by treatment decision-making; (b) lack of clarity regarding treatment and diagnosis; (c) lack of symptom management resources; and (d) concerns regarding English fluency and medical terminology. Facilitators included: (a) self-advocacy for treatment options and quality of life resources; (b) feeling comfortable asking care team questions; (c) having a skilled support system; and (d) avoiding unhelpful medical information. Patient activation levels varied, but all participants expressed a desire to be proactively included in decisions throughout care.

Conclusions: Results suggest that patient activation may be promoted in this population through the provision of information/resources that are timely, accessible, and relevant to their care needs and active inclusion of patients in decision-making. Findings will guide culturally-adapted interventions that increase patient activation and shared decision-making.

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1 | Background

Individuals living with metastatic cancer are a growing population in the United States, projected to rise from 623,405 in 2018 to 693,425 by 2025 due to advances in life-prolonging oncologic treatments [1]. Despite their complex care needs, patients with advanced stage solid tumors receiving non-curative treatment remain underrepresented in research regarding health-related quality of life and survivorship [2]. This underscores the need for tailored patient engagement and management strategies.

Patient activation and shared decision-making are well-recognized constructs in patient-centered care. Patient activation, a modifiable factor, is established when patients are equipped with the necessary knowledge, skills, and motivation to meaningfully participate in managing their health [3]. Shared decision-making, a process in which patients and their healthcare providers are both participants in making decisions, complements patient activation [4]. These two constructs, when acting synergistically in an accessible, well-organized, and responsive healthcare system, improve patient satisfaction and clinical outcomes of chronic conditions, including increased confidence in managing side-effects during cancer treatment. Higher scores on the Patient Activation Measure (PAM) correlate positively with socioeconomic status [5–8].

Hispanics/Latinos are the U.S.'s largest racial/ethnic minority, comprising 19.1% of the U.S. population (63.7 million) [9]. They are disproportionately impacted by different social determinants of health that may impact patient activation, including lower health literacy, socioeconomic status, levels of educational attainment, and access to healthcare, as well as language barriers and structural and perceived discrimination [10]. Hispanic/Latino cancer patients are more likely to be diagnosed with advanced disease and report worse quality of life and symptom burden compared to non-Hispanic/Latino Whites, yet they remain underrepresented in oncology research and clinical trials [11].

Little is known about patient activation and shared decision-making among Hispanics/Latinos with metastatic cancer, and studies on the implementation of shared decision-making have largely focused on the perspectives of providers rather than patients [12]. This secondary analysis aimed to identify barriers and facilitators to patient activation and shared decision-making to inform future interventions that improve the quality of life and clinical outcomes for this population.

2 | Methods

As part of a larger project surrounding palliative care needs, beliefs, and experiences among English- and Spanish-speaking Hispanics/Latinos with metastatic cancer, the study team conducted a secondary analysis on the themes of patient activation and shared decision-making and examined barriers and facilitators to both. Understanding how patients engage in this was a central aspect of the project, as activated patients are more

equipped to manage their symptoms and have better understanding of their treatment and prognostic options.

2.1 | Participants

Participants for this study were derived from a National Cancer Institute-funded project on palliative care among Hispanics/Latinos with metastatic cancer. Eligibility criteria included: (a) self-identifying as Hispanic/Latino, (b) 18 or older, (c) having a medical chart confirmed diagnosis of a metastatic solid malignancy (d) undergoing non-curative/palliative cancer treatment, (e) receiving care at the University of Miami Health System, and (f) able to speak English or Spanish.

2.2 | Recruitment and Screening

Patients at the University of Miami Health System can voluntarily enroll in the Consent to Contact Registry, managed by the University of Miami Clinical and Translational Science Institute, to be contacted for qualifying clinical studies. Potential participants were identified through this registry using ICD-10 codes. Staff pre-screened candidates via the electronic health record to confirm stage IV. Eligible participants were then recruited via phone and underwent further eligibility screening. The study team aimed to have an even split between self-identifying male and female participants, which was achieved.

2.3 | Procedures

This study was approved by the Institutional Review Board at the University of Miami Miller School of Medicine (STU 20210745). Individuals completed informed consent prior to participation. A licensed clinical psychologist (PIM) with oncology expertise facilitated three 2-h focus groups using a standardized semi-structured format with open-ended questions assessing supportive care needs, communication with the care team regarding quality of life and symptom management, referrals to specialty palliative care and other specialists, and beliefs, attitudes and experiences regarding palliative care (Supporting Information S1 for Interview Guide). Focus groups were conducted remotely via Zoom, audio recorded, and transcribed for qualitative analyses. Participants were compensated \$50.

2.4 | Data Analysis

Focus group transcripts were analyzed using rapid qualitative analysis. This validated approach facilitates rigorous and efficient analysis of qualitative data, particularly useful for implementation science [13, 14]. Interview Summaries were created for each focus group using a standardized template to organize key findings and quotes. Authors (J.M., P.I.M., H.N.M., and M.P.) completed *individual* Interview Summaries for each focus group, which were reviewed and synthesized into a *group consensus* Interview Summary during a team meeting. The

study team then created Interview Summary Matrices to extract key themes by transferring information from the *group consensus* Interview Summary into a spreadsheet to display participants' responses by interview domain. The research team used an iterative, consensus-driven process to identify key themes, including patient activation and shared decision-making. This paper provides a secondary analysis to further explore their implications.

3 | Results

3.1 | Sample Characteristics

Twenty-two patients participated in focus groups (two English-speaking groups: $n = 13$, one Spanish-speaking group: $n = 9$). See Table 1 for characteristics of the study sample.

3.2 | Barriers

Participants reported various barriers to patient activation and shared decision-making during cancer treatment. A key theme was the overwhelm of treatment decisions and unclear diagnoses. While many sought more prognostic information, others preferred not to know, highlighting diverse disclosure preferences. Illustrative quotes for barriers are in Table 2.

3.2.1 | Uncertainty and Lack of Information

Participants noted a lack of information from healthcare providers. Participant 203 remarked on the fear and anxiety stemming from insufficient information about future treatment steps:

I don't think the doctors want to tell you anything about the next step if you're not there. [...] I think the lack of the information, and that's what scares me more because I don't know, and my doctors say that it's like, 'Yeah, you need to take day by day one day at a time.' Yes, but I still want to know what's going to happen.

3.2.2 | Need for Proactive Symptom Management

Participants expressed dissatisfaction with the reactive nature of symptom management. Participant 004 shared:

They don't really give you that supportive therapy, they don't talk about supplements that you can take to help with the joint pain, or something to help with the irritability. It's just kind of like this is what to expect, so just figure out how you're going to deal with that.

The lack of proactive support led some participants to seek information online, sometimes finding distressing details about their condition.

TABLE 1 | Sociodemographic and medical characteristics.

	Total N (%)
Total	22
Age, years	
Median	55
Mean (SD)	53.45 (11.85)
Range	32–71
Gender	
Female	11 (50.0%)
Male	11 (50.0%)
Country of origin	
Colombia	8 (36.3%)
Cuba	5 (22.7%)
Brazil	3 (13.6%)
Peru	1 (4.5%)
Venezuela	1 (4.5%)
Mixed	4 (18.2%)
Language preference	
English	13 (59.1%)
Spanish	9 (40.9%)
Time since diagnosis, years	
Median	3.5
Mean (SD)	5.14 (6.17)
Range	0–27
Primary cancer sites	
Breast	5
Lung	4
Colorectal	4
Head and neck	3
Kidney	2
Skin	1
Bladder	1
Other gastrointestinal	2
Current cancer treatments ^a	
Chemotherapy	14 (63.6%)
Immunotherapy	4 (18.2%)
Targeted therapy	3 (13.6%)
Hormone therapy	1 (4.5%)
Radiotherapy	1 (4.5%)
Other	1 (4.5%)
None	1 (4.5%)
Relationship status	
Married	16 (72.7%)
Single	3 (13.6%)
Separated/divorced	2 (9.1%)

(Continues)

TABLE 1 | (Continued)

	Total N (%)
Widowed	1 (4.5%)
Parental status	
Children (adult or minor)	20 (90.9%)
No children	2 (9.1%)
Education level	
High school degree	2 (9.1%)
Some college/technical/associate's degree	5 (22.7%)
Bachelor's degree or higher	15 (68.2%)

^aIndividuals could select more than one current cancer treatment.

3.2.3 | Language Barriers

For participants who spoke English as a foreign language, understanding medical terminology posed a barrier to effective communication and participation in their treatment. Participant 206 highlighted the importance of having a healthcare provider who could communicate in their native language:

The PA of my oncologist is Brazilian too. And it helped a lot. And I can't imagine if I didn't have any kind of more or less [language support] [...] I speak English more or less, but the thing of the vocabulary of the cancer situation is different.

3.3 | Facilitators

The study identified several facilitators of patient activation and shared decision-making. Key themes included self-advocacy and having strong support systems. Illustrative quotes for facilitators are in Table 2.

3.3.1 | Self-Advocacy

Participants stressed the importance of self-advocacy, which was more attainable when they felt comfortable asking their care team questions. Participant 007 emphasized that self-advocacy ensures personalized care:

We have to advocate a lot on our own to kind of navigate what works best for our unique condition because if we were all the same, then we'd all seek the same help. But in the condition that we're in today, we all have a uniqueness in how strong our bodies are and our minds.

Participant 010 demonstrated that self-advocacy is important for patients to make treatment decisions that are in line with their goals of care:

They go through some kind of a protocol, the doctors, and sometimes you've got to push them. Like I said,

you've got to be your own advocate, and that's something that has to change because doctors have to—I understand they have a lot of patients and so forth, but they also have to understand that just because a lot of patients have not had the treatments work for them, sometimes they do, you know? Like in my case, the fourth one did.

3.3.2 | Strong Support Systems

Another facilitator identified was having a strong support system, as skilled caretakers can assist with care management, and friends and family motivate patients to be active participants in their treatment. For Participant 107, having children who “give [her] strength, allow [her] to continue” and kept her from being in “bed thinking about how many hours I have.” Participants expressed a need for support services to educate and assist caregivers so that patients can continue to be cared for by them. Participant's support systems were also helpful for navigating and interpreting medical information.

4 | Discussion

This study highlights that patient activation and shared decision-making among Hispanic/Latino patients with metastatic cancer can be enhanced by reducing medical jargon, providing timely and accessible information, supporting caregivers, and fostering an environment where patients feel comfortable participating in their care. While activation levels varied, all patients expressed a desire for proactive involvement in symptom management and treatment decisions. Despite existing guidelines, findings from our study reveal gaps in their application to this population. Hispanic/Latino patients have had limited opportunities to share their perspectives on this subject, and assumptions about best practices for their treatment cannot be made without rigorous scientific inquiry. As metastatic cancer therapies improve and patients live longer, opportunities for patient activation and priorities in medical decision making may change, increasing the need for continued study.

Patients' concerns about understanding their condition and medical terminology align with studies suggesting language-concordant care may improve health outcomes. However, more research is needed to determine if increasing language concordance is more effective than other interventions, such as targeting health literacy in minority groups [15]. Notably, patients did not express concerns regarding cultural competence, likely due to the study's setting, where many providers were Hispanic/Latino and Spanish-speaking. This contrasts with a California study attributing lower palliative care utilization to a lack of Hispanic/Latino providers [16].

4.1 | Clinical Implications

Barriers and facilitators to patient activation and shared decision-making can be addressed through increasing access to and effective integration of specialty palliative medicine, a

TABLE 2 | Illustrative quotes by *Barrier* and *Facilitator* themes.

Themes		Illustrative quotes
Barriers	Uncertainty and lack of information	<p>P109: So psychologically that affects you because it is a clash between what I thought, for example, that [physician] told me, “you are already well, the treatment you have to do is immunotherapy, but monotherapy for you is a more preventive issue. Everything you had has been removed, you don’t have cancer now, you can live your normal life”.</p> <p>And suddenly another doctor would come and tell me “But you had metastasis in vertebra 9. No, that means that you will never be cured, you know that, right?” [...] I am not understanding anything because they are two completely different things, and well if one does not understand medicine ... In my case, I am an economist. Clearly, of medicine, I knew nothing. So, you do find yourself in dilemmas at times because the versions are very different, and you don’t know which way to go because you don’t have the criteria to decide</p> <p>P202: I feel like I just don’t have that peace of mind to know that I’m making the right decisions, I guess, because I don’t have that information</p> <p>P206: Frankness in the communication between the doctors and a patient. [In] the beginning, I thought, “No, this is the American way to treat patients with the whole truth.” After a while I figured out that it wasn’t the truth. [...] Maybe it wasn’t the American way to say in a frank way things</p>
	Need for proactive symptom management	<p>P111: They asked me for a bone density, I did three in a year, the last one nobody told me anything and I started to review my report, I entered the chart and I saw my report and it said that I had a completely negative grade in my osteoporosis, that it burst in a matter of three months. The doctors had never seen a report before, I was the one who told them, I have osteoporosis</p> <p>P205: [Radiation oncology was] also pretty good with talking about the at the side effects, and what I could do to improve the side effects [...]. But some stuff, yeah, it’s like they’re honest, you know. You just have to wait and let the radiation damage heal, and maybe it’ll get better, and it’s possible it won’t get better, but at least knowing is everything</p>
Facilitators	Self-advocacy	<p>P004: Like I mentioned before, I was doing all holistic. I did not believe in all of this medical stuff for a long time. Then I went to nursing school. I’ve been a nurse for almost seven years, and I realized there’s so much more, from a medical perspective, don’t just have the time to really explain to a patient. It is a flawed medical system, 100%. I wish it was better. I wish the communication between physicians and staff to patients to help just understand was better. [...] First and foremost, you have to advocate for yourself. That will never change. Like, if you’re not looking out for you, you cannot rely on a member of the medical community to do what it is that you are responsible for doing. There are so many people out there that are just not compliant, and you cannot just mind read that this person really wants help and this one doesn’t. So, you have to do that for yourself</p> <p>P104: So I have been looking for other things, I don’t just follow what I hear at the hospital; I don’t let the doctor tell me everything I have to do, no, I am the one who is most interested in all that. I have been searching, but I think it is fundamental that patients should know everything available so that they can have a better quality of life, more treatment, and other treatment options, all of that is very important for the patient to have</p>
	Strong support systems	<p>P202: “I have a great friend and a group of friends- about three people that I rely on heavily because they do the homework for me [...] They’re really intellectual. I think people that can make a good decision and get some good facts and not go through, you know as Participant 205 saying, don’t go to that rabbit hole, all these unpublished things that are just ... It’s just crazy what’s out there.”</p> <p>P113: When I got sick was when I was going through a divorce, I don’t want to blame it on my ex, but I got very weak and my mind did not work except through what was going to happen in the divorce. I think the mind is very strong, it is not that one attracts diseases, but in part, it weakens you a lot, then I think everything is in the mind that helps a lot to one’s mental state, it is necessary to be very positive, it is necessary to be strong and grateful for each day we have and not to put negative thoughts, I know there are some</p>

model of care that centers patient activation, including in symptom management, treatment decision-making, and caregiver support in the context of serious illness, into the care of patients with metastatic cancer [17]. While guidelines exist for the provision of palliative care to patients with stage IV cancer, disparities remain; in a study with over 2300 adults, 75% of Hispanics/Latinos reported having never heard about palliative care (compared to 49% of non-Hispanic/Latino Whites) [18]. Our findings emphasize that research and interventions addressing disparities in access to palliative care for Hispanics/Latinos are necessary. These results also support the idea that a skilled social support system assists with care management and facilitates patient activation. Family involvement in care is associated with higher self-efficacy and lower levels of stress and depression among patients, while low caregiver involvement reduces treatment adherence even among patients with higher levels of patient activation [19, 20]. Future interventions cannot ignore patient's support systems, and additional research is necessary on the specific needs of caregivers for Hispanic/Latino patients with metastatic cancer. The effectiveness of culturally adapted interventions compared to standard, evidence-based approaches across racial/ethnic groups should also be assessed in the future.

4.2 | Limitations

Strengths of this study include the inclusion of both English and Spanish-speaking participants from diverse countries of origin, tumor types, and current cancer treatments. However, geographic limitations restrict generalizability to the broader Hispanic/Latino population. As this was a secondary analysis, results should be interpreted cautiously and validated in future studies directly assessing patient activation and shared decision-making.

5 | Conclusion

Providers can enhance patient activation by offering timely and accessible information and resources and fostering active patient involvement in treatment decisions. Future research will examine healthcare providers' perspectives on barriers and facilitators to patient activation and shared decision-making in this population. Findings will guide interventions to improve patient activation and shared decision-making for Hispanics/Latinos with metastatic cancer.

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Conflicts of Interest

The authors declare no conflicts of interest.

Data Availability Statement

The data that support the findings of this study are available on request from the corresponding author. The data are not publicly available due to privacy or ethical restrictions.

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Supporting Information

Additional supporting information can be found online in the Supporting Information section.