



Experiences of Undocumented Immigrants with Hematologic Malignancies Denied Access to Hematopoietic Stem Cell Transplant

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"The most ironic thing of all is when you realize that it's not for anything other than money. You realize that whoa, it's not because my country doesn't have it... it's because money gets in the way. So one says whoa, if I had money, I would live, but if I don't have money, I die. It's hard when you see human life reduced to that."

Objectives

➤ To describe the lived experience of undocumented immigrants in Colorado with hematologic malignancies who have been unable to receive recommended treatment with hematopoietic stem cell transplant (HSCT) due to immigration status.

➤ To add rigorous qualitative evidence to the growing body of research around access to care for undocumented immigrants.

Introduction

For a patient with a new cancer diagnosis, a difference in immigration status may be the difference between life and death

POLICY IN PRACTICE

➤ Undocumented immigrants face additional **challenges accessing health insurance**, as they are excluded from receiving federally funded benefits ⁽¹⁾
Despite contributing financially to these policies
--> nearly \$12 billion annually to Medicaid ⁽²⁾

➤ The majority **rely exclusively on Emergency Medicaid** for health insurance
In rare cases, they may have employer-sponsored health insurance, provided they remain employed during their illness, which is often not possible.
They are unable to receive benefits from the Affordable Care Act

Emergency Medicaid

➤ State level policy based on 1986 Federal Law: Emergency Medical Treatment and Active Labor Act (EMTALA)
➤ Provides **coverage for uninsured patients** who otherwise qualify for state Medicaid benefits but do not meet citizenship requirements
▪ Covers: Inpatient hospital admission for life or limb threatening medical conditions, active childbirth
▪ Does Not Cover: Outpatient follow up, Medications

HEMATOPOIETIC STEM CELL TRANSPLANT

➤ Indicated for many hematologic malignancies including leukemias, lymphomas, and multiple myeloma which are **life-threatening and difficult to treat**
- Annual incidence in the US (2021, American Cancer Society)
Leukemia: 61,090 cases, Lymphoma: 90,390 cases; Myeloma 34,920
- Five-year survival rate **with standard treatment** (2016, National Cancer Institute)
Leukemia: 66%; Non-Hodgkins Lymphoma: 75%; Myeloma 55%

➤ In many cases, **HSCT is the only potentially curative therapy and significantly improves outcomes**
For patients with intermediate to poor-risk AML, undergoing **HSCT halves the risk of relapse** ⁽³⁾

➤ Patients often initially present to the Emergency Department with life threatening symptoms
▪ **Leads to admission to hospital and enrollment in Emergency Medicaid**
▪ **But to undergo HSCT, disease must first be controlled with chemotherapy (in remission).** When in remission, patients are stable and do not qualify for Emergency Medicaid

Stem Cell Transplant is NOT covered by Emergency Medicaid.

Therefore, the majority of undocumented immigrants are **unable to receive HSCT** due their documentation status, even if it is medically indicated and is **the only possible cure for their cancer.**

EXPERIENCE WITH END STAGE RENAL DISEASE AND DIALYSIS

➤ Undocumented patients with ESRD were previously unable to access routine dialysis, due to similar limitations of Emergency Medicaid
▪ Their only option for dialysis was to present to the Emergency Department meeting criteria for emergent dialysis

➤ Prior qualitative analysis of undocumented patients with ESRD demonstrated themes including death anxiety associated with weekly dialysis as well as family and social consequences, among other topics ⁽⁵⁾

➤ This contributed to modification of Colorado's Emergency Medicaid policy to include routine dialysis under covered conditions

Methods

From 2021-2022, key stakeholders (healthcare providers within oncology specialty services) identified possible participants, who were reviewed for the following inclusion criteria:

- 1) No legal residence in the US
- 2) No form of health insurance
- 3) Diagnosis of a hematologic malignancy that is medically appropriate for stem cell transplant
- 4) Preferred language is Spanish or English

Interviews were recorded and transcribed. Interviewers made memos immediately after the interviews.

All authors reviewed data independently to create themes, then held serial meetings to refine themes. This allowed for a consensus reflecting the data's full meanings, depth, and complexity.

Results

Themes and Subthemes	Illustrative Quotations*	*Translated from original Spanish
1. Cancer and immigration status		
<i>Fatalism and Resignation to Inadequate Care</i>	"Why should I worry about something that I cannot get because of my circumstances? ... And I'm not gonna – I'm not gonna put that in my mind that it does exist and because of my situation, I'm not getting it. I'm getting something, period, and I'm grateful" "Maybe if I had this transplant, things would be much easier for me, much faster. Notice that the bones...we didn't expect it, that my bones would be broken because of this illness. So it's sad but also good to know that they're doing something for me, that someone is caring for me, it comforts me."	
<i>Feeling Dehumanized When Health Insurance Determines Ability to Live</i>	"You see how your illness can advance and progress and every time, you're going to feel ill, and the medications exist in the world, but...you don't have access to them."	
<i>Debilitating Cancer Symptoms Disrupt Legal Immigration Process</i>	"The process of getting asylum is, unfortunately, lamentably, something that we can't continue. We had already signed our first court date, however, we need some lawyers that can represent us...because of my illness, like I told you, we can't keep going forward."	
2. Appreciation and Gratitude for Advocacy		
<i>Awareness of physician advocacy</i>	"If it wasn't for the doctor, I would still [be chained up in the hospital after being detained at the border]. He arranged to help me with all of that."	
3. Pride and Purpose in the United States		
<i>Desire to make a positive impact on society</i>	"The hope and the aim is that we can become documented, and we can make a stable life here and to get my treatment and that we can contribute with an example to our son and be part of society, be good citizens, and contribute." "I work every day, I don't rest a day. I pay taxes every year. This year I had to pay \$1,495." "Whatever you pitch in that might help another person—it's a chain we can all build."	
<i>Pride in Immigrants' Contributions to the US workforce</i>	"So, I don't understand why Americans don't like immigrants. Because immigrants are the people that make this country [work]. I'm not asking anybody to believe me, but because I have experienced it, I really, really know. We work."	
4. Adversity Related to Cancer Care and Treatment		
<i>Feeling dismissed and delayed diagnosis</i>	"I had gotten an appointment for sinusitis. But I was doing poorly, and I felt bad, I had pain in my knees, my hips. I'd gone to the emergency room but they didn't diagnose me with anything... I told them no, that I didn't need an appointment for sinusitis, that I needed blood tests because I felt very bad... And this is when I was diagnosed with leukemia." "[Before knowing my diagnosis] I went to the hospital...and they gave me some pain pills, nothing more."	
<i>Emotional and Physical Burden</i>	"Sometimes, I go to the supermarket and buy a bag of potatoes. And I eat one for breakfast, one for lunch, one for dinner. And I send the money [for my children] to go to school." "Now I'm trying to find how I can work, I know that I don't have [immigration] papers to work but I'm trying to figure out how to work... So I was trying to find all of this information and all that..."	
<i>Burdening Family</i>	"There are people who would simply prefer to die rather than leave their family with such debt, because that's another thing." "My sister felt it more, really breaking the news to my parents was also difficult. I didn't know how to tell them." "My sister is busy... sometimes I know that [asking for a ride] is going to complicate her life. And the social workers told me about the bus, but then they told me to not take the bus because there's a high risk of infection now that I am prone to getting sick, as my immune system is weak, so I didn't take the bus. So, I'm looking for help from my friends, asking them if they can give me rides."	
<i>Social Isolation</i>	"When you come to the hospital, there's a different type of food. And when you find yourself in the hospital, you say: I wish that someone would come and they would bring something from home. This is what I felt. My wife didn't have time; she had just given birth at that time. She couldn't come. My brothers, they alternated coming to see me. Others, since they worked, didn't have time."	
5. Support and Coping Mechanisms		
<i>Embracing Positivity</i>	"I want to continue fighting... you have to fight to the end." "I try to make every day better, I try to make every day a day filled with hope, with positivity... I try to infuse life into my cells... I feel like that's what's kept me so far in this state of positivity." "One never knows what's going to happen. But because if you assume everything will go well, it will go well. But life has its ups and downs."	
<i>Religion as a source of comfort</i>	"There are always angels that come into one's life, people always come with good vibrations, positivity, with good news, and when one is the most down, God sends an angel to strengthen you and say, 'yes we can, yes we go forward, we're here for something.'" "I've been thanking God a lot for this disease, because ... otherwise I wouldn't have thought about Him so much." "The hope that God gives for the future, for sick people, for dying people, for the whole Earth and for all life on earth. That fills you with hope, motivation and a positivity to see the world."	
<i>Critical Support from Family and Friends</i>	"There are times that [my mother-in-law] has to lend us her vehicle so we can help ourselves. So she has to leave work to bring us." "Of course, I have the support of my wife, my son, of my family. They're not here but they're out there, they're outside of the United States but they call me every day, they're very attentive."	
<i>Gratitude for Compassionate Care</i>	"[Health care providers] opened doors for me, they didn't close them. That's another thing that I also saw. That at the least... they see you, that I just arrived, they cleaned the IV port, they changed my bandage. For me this is wow, as I see it, they're attending to you, they're doing little things for you, whatever is needed for wellbeing. And they gave me a list of medications that I have to buy." "Every time they come in to give me my medications, I would ask a question then I would take it. And – and then I said to explain everything to me. The nurses were really great about it..."	
<i>Appreciation for Care that is Unavailable in Home Country</i>	"The treatment has been great, the attention has been very good. I don't have anything to say against the treatment I've gotten here. On the contrary, I'm very grateful." "If I had stayed in Mexico, who knows if I would still be alive. And here, thank God, I get treatment for now and so I've had more support support..."	

Population

Patient Characteristics	Value (N=7)
Age, mean (SD), y	44 (15.8)
Females, no. (%)	2 (29)
Country of Origin	
Mexico, no.	3
Venezuela, no.	2
Bolivia, no.	1
Jamaica, no.	1
Preferred Language is Spanish, no. (%)	6 (86)
Educational Level	
Completed high school, no. (%)	5, (71)
Completed college or postgraduate education	2, (29)
Percentage of Immediate Family Outside U.S., mean (SD)	67 (20)
Worked Hourly Prior to Cancer Diagnosis, no. (%)	6 (86)
Type of Cancer	
Multiple Myeloma, no.	2
Acute Lymphoblastic Leukemia, no.	2
Lymphoma (B-Cell lymphoma, Non-Hodgkins Lymphoma), no.	2
CML, no.	1
Lost job due to cancer, no. (%)	7 (100)

Discussion

- Undocumented individuals with hematologic cancers in Colorado are forced to navigate the complicated financial, logistical, and emotional implications of living with cancer and lacking health insurance, which is magnified by their immigration and socioeconomic status. Most interestingly, the process of seeking asylum and legal status was often delayed for these patients, as they were so overwhelmed simply trying to find care and treatment.
- All of the patients interviewed had to stop working at their place of employment during their illness. Six of the seven worked for hourly wages. Reasons for stopping work include symptoms of cancer and side effects of treatment including fatigue and time needed for medical appointments. This is a common theme among those undergoing treatment for cancer. The majority resume employment once in remission.
- Despite this, they expressed deep gratitude for the care they *were* able to get. They felt supported by healthcare workers, family members (both documented and undocumented), and through their spirituality. Many participants noted that they wanted to give back to the communities in the US and to the country as a whole if they survived their cancer.

Undocumented immigrants in our study were grateful for the care they were able to receive, but also **recognized that they received a sub-standard level of care, especially when it came to Stem Cell Transplant**

POLICY IMPLICATIONS

- Increasing access to comprehensive cancer care including HSCT provides equitable, high-quality care to Coloradans and benefits the state's economy. Healthcare providers would be able to choose guideline-based treatments, including HSCT, based on medical indications rather than immigration status. This would save patient lives and make Colorado a national leader in equitable, financially-secure healthcare.
- Several other states provide cancer coverage under state Medicaid or Emergency Medicaid such as, CA, MA, WA, WI and MN. Some states have simply added "cancer treatment" as a qualifying diagnosis for Emergency Medicaid, while others were able to achieve this change through legislation (CA).
- As clinicians, we will need to partner with policymakers and government officials to work toward change together. In our instance, we plan to reach out to the State's Health Care and Policy Financing committee as well as lawmakers (state representatives) and policy experts within our academic institution to enact change.
- The process of enacting change involves networking with multiple individuals until a strong connection can be made with individuals within the local government, policy experts, or others who have the power to enact change.

References

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5. Cervantes L, Fischer S, Berlinger N, Zabalaga M, Camacho C, Linas S, et al. The illness experience of undocumented immigrants with end-stage renal disease. *JAMA Intern Med*. 2017;177(4):529–35.

"This is the country with the most resources maybe in all of history, and these resources are only for those who can take advantage of them."