

UNC LINEBERGER COMPREHENSIVE CANCER CENTER UNC CANCER CARE

Meeting the Needs of Undocumented Patients with Cancer in North Carolina

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Presenter Disclosure

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I have no current or past relationships with commercial entities.
I have received no speakers fee for this learning activity.

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Explain Barriers, Describe care concerns, and Discuss resources

Today's objectives:

- Explain barriers experienced by undocumented and non-English speaking patients seeking cancer care in North Carolina
- Describe ethical and practical concerns for delivering comprehensive cancer care to undocumented patients with cancer and their families
- Discuss UNC Medical Center and North Carolina community resources to assist undocumented patients and their families to receive best practice cancer care

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Who are the Undocumented in General?

Undocumented individuals are persons living in the U.S. without legal permission

They may have:

- Come to U.S. fleeing extreme poverty and seeking employment opportunities
- Fled their home country due to imminent threats of violence from criminal gangs, sociopolitical groups, or DV perpetrators
 - Note: They may be unable to afford legal representation or unable to access free immigration legal support in order to file for asylum, U visas or T visas
- Been living in the U.S. for many years/decades, or they may be a relative newcomer
- Overstayed a travel or student visa, and now live as undocumented
- A "mixed status" household (i.e., with family members who are legal permanent residents or U.S. citizens)



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Who are the Undocumented in North Carolina?

North Carolina has 321,000 undocumented immigrants (out of 11.5 million in the U.S.)

- 83% are from Mexico or Central America; 8% from Asia; and the remaining are from Africa, South America, Europe/Canada/Oceania, and the Caribbean
- Of ages 15 and older: 43% reside with children under the age of 18
- Of ages 16 and older: 69% are employed, 5% are unemployed and 26% are out of the labor force (i.e., elderly or full-time homemakers with young children)
- 36% are homeowners
- 71% are uninsured

Data obtained from the Migration Policy Institute: Profile of the Unauthorized Population: North Carolina

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Unique Challenges for Undocumented Cancer Patients

Language and health literacy barriers

- Nearly half undocumented immigrants 5 yrs or older in NC report that their English speaking proficiency is "not well/not at all"
- Difficulty accessing primary vs. specialty vs. emergency care b/c they lack of understanding of the US healthcare system

Fear of accessing medical care and financial assistance programs due to immigration status

- Fear being targeted by U.S. Immigration and Customs Enforcement (ICE), or having problems with their immigration applications for a green card, asylum or other legal status
- While most undocumented immigrants are ineligible to obtain full Medicaid or other benefits for themselves, they may fear accessing programs for which they *are eligible*, such as Emergency Medicaid, financial charity programs, and care at federally-funded low income clinics, due to their misunderstanding of federal policies
- Also, young undocumented immigrants (the "Dreamers") eligible for work permits under the Deferred Action on Childhood Arrivals (DACA) program are currently excluded from Medicaid and CHIP and from ACA insurance benefits.
- The North Carolina Justice Center is the best resource for more detailed information on immigrants rights to access health care and health insurance

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Unique Challenges for Undocumented Cancer Patients

Transportation barriers



- Expired (or no) valid driver's license, and fear of deportation if pulled over
- Typically working jobs without PTO or even permission to take time off work to bring them to their clinic appointments

Not eligible for SSD/SSDI, Medicaid, Medicare, ACA insurance plans, food stamps, or other federal and state government programs. EXCEPT those obtained by eligible family members in household
J. Hawes, B.A., M.S. (2019), North Carolina Justice Center

- They themselves are not eligible for these programs, but their US citizen children or other household members with legal status are! Reassure them of this, and that it will NOT hurt their own chances of getting legal status later on.

Difficult to obtain documents to prove NC state residency for charity care programs and community clinic sliding scale fee programs

- Resources to obtain needed documents include their country's consulate to obtain a new passport from their home country, pay stubs or letters from employers with NC address information, and school enrollment information for the k12 children of undocumented immigrants, which can be proof of NC residency status.






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Practical Issues in Cancer Care for Undocumented Patients

Undocumented Patients' Practical challenges across a day of clinic appointments:

- Registration and check-in may not understand their legal status or needs
- Check-in and navigation between clinics in English
- Check-out and scheduling in English
- Pharmacy Distinctions (i.e., Outpt vs. Specialty vs. Manufacturer's Assistance- each with their own applications)
- After hours urgent oncology care needs more difficult to access



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Composite Clinical Example of the "Life of Undocumented Patients" with Cancer

An undocumented female in her late 50's with advanced GI cancer who is covered by the hospital charity care and pharmacy assistance programs, declines rapidly when her undocumented adult daughter and sole caregiver is one day, unexpectedly, detained by ICE and taken to a detention center out of state. Shortly afterward, the Pt's pharmacy charity benefit expired, but without her daughter's help she didn't know how to navigate the system in order to renew it. As a result, she couldn't afford her Rx's for palliative medicines, and simply stopped taking them without telling anyone. She declined rapidly as a result, and required emergency hospitalization for intractable pain and nausea.

Not only was she critically ill, but she was devastated by her daughter's detention, and lacked the caregiving support she needed to return home after her symptoms stabilized. However, because she was not eligible for long-term care Medicaid, and could not discharge into a skilled nursing facility either.

Knowing she needed caregiver in order to return home, the Pt's oncology provider and nurse navigator formulated a letter of medical need for her daughter to be permitted to return home to provide care, which was forwarded to the family to utilize as additional support to assist in obtaining legal representation at the detention center. In addition, other relatives were enlisted to help bring her home and provide the necessary care while her daughter was unavailable.

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Composite Clinical Example 2

An undocumented male in his early 30's with B-cell Acute Lymphoblastic Leukemia is having disease progression with the available oral chemotherapy medications (which he is assisted to obtain through the manufacturer's assistance program). He is not eligible for a bone marrow transplant because the hospital charity care program does not cover BMT. Nor does emergency Medicaid.

He is the sole custodial parent of two minor age children who are US citizens, as their mother is deceased. Both the oncology provider team and the social worker struggle to help him face the need to make legal guardianship plans for his daughters, while also supporting his hope that sub-optimal treatment will keep him alive as long as possible. If he had been able to access a BMT, he would have had an excellent prognosis.



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Composite Clinical Example 3

An African female in her mid 40's who overstayed her student visa years ago, and is now undocumented, delays having her breast mass evaluated because she is uninsured and fearful of entering the U.S. health care system. By the time she comes to the clinic, she had a fungating mass that is diagnosed as Stage IIIC advanced breast cancer.

She was approved for the hospital charity and pharmacy assistance programs, and able to obtain chemo, surgery, radiation and subsequent immunotherapy over the course of a year. However, her psychosocial situation is extremely precarious throughout. She lived alone in a small apartment, having worked previously as an in-home caregiver to elderly individuals, and was estranged from her relatives who live in other parts of the country. Over time, she became too ill to work, and without any income, dependent on foundations, her church, and one-time grants to prevent eviction (which her landlord filed in the court once). The oncology nurse navigator and social worker provided ongoing support, assistance with grant applications, and gas cards/lodging/parking assistance. Nevertheless, she missed many treatment appts due to car break-downs and lack of bus in her rural area of the state.

When her illness progressed, she was hospitalized multiple times for acute problems, and only accepted into home hospice in the final days of her life, when she finally agreed to inform her relatives of her advanced illness.



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Practical and Ethical Challenges for the Oncology Provider

Localized vs. Invasive vs. metastatic cancer

- How will their illness and the treatment plan likely affect their ability to work and care for their loved ones?

Curative vs. palliative treatment

- Do they fully understand the difference between treatment for curative vs palliative intent, and the change that occurs when cancer becomes metastatic
- There are often substantial cultural differences between immigrants' understanding and expectations, and those within the U.S. Cancer Care system
- Advance planning is often avoided, although desperately needed, and it could be perceived negatively as "giving up hope"



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Practical and Ethical Challenges for the Oncology Provider



Medication regimens and the specific reasons to take different medications

- Pill bottles should have labels written in the patient's language (with help of an interpreter)
- Provide clear instructions on how to access provider team if they have questions about their symptoms or medications
- MyChart or other patient web-based portals are not likely feasible means of communication for them

Primary care is essential for non-cancer-related medical needs

Limited options for end of life care



- At end of life, undocumented patients often receive more aggressive care, including prolonged hospitalizations, hospital death, and intensive care unit admissions (Jaramillo & Hui, 2016)
- Access to hospice for uninsured patients is only possible through charity unless patients have the ability to pay. Thus, undocumented patients may be left with emergency departments and acute care hospitals as their only recourse
- A difficult decision at EOL is whether the patient should voluntarily return to his country of origin or not

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Supporting Undocumented Patients in your NC Cancer Center

- Provide language interpretation
- Connect patients with ancillary staff who are native speakers whenever possible (i.e., financial counselors, lay navigation volunteers, resource center staff) because it helps them feel more comfortable and welcomed
- Spend time establishing rapport and a sense of safety
- Navigate patients closely within the cancer center and across the health care system to prevent getting lost through the system cracks
- Oncology providers and nurses are in a great position to connect undocumented patients and families to social workers and financial counselors, who can assist them with charity care programs and pharmacy assistance programs
- Connect patients and their families with an oncology social worker and/or financial counselor
- Connect patients and their families with immigrant centers and other community resources in their area
- Seek to understand and be up to date on resources (We will review Resource Slide in depth)

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“Humanitarian Visa” and “Medical Deferred Action” Letter Requests



Both documented and undocumented immigrant patients with cancer often request medical letters of support to apply for a “humanitarian visa” for a family member to come and help care for them for a limited time

Also, undocumented parents of children receiving cancer treatment request medical letters of support to be able to remain in the country as caregivers while their children are receiving care

Letter from a medical doctor needs to state:

- diagnosis, treatment modalities, prognosis, duration of treatment
- financial assistance programs covering treatment, which would not be available in their home country
- why the patient needs a family member to come to the US in order to care for patient here in the US, or to stay in the US for this care (i.e., they receive charity care and would not be able to afford or access care in their home country)

US Citizenship and Immigration Services Website, Guidance on Evidence for Certain Types of Humanitarian or Significant Public Benefit Parole Requests

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NC and Federal Resources for Undocumented Patients with Cancer


Interpreter Services and at your Medical Facility/Hospital

NC Justice Center
Has a Fact Sheet and frequently updated information about the legal rights that immigrants (included both documented and undocumented) have to access medical care.
<https://www.ncjustice.org/projects/immigrant-refugee-rights/project-resources/immigrant-health/>
<https://www.ncjustice.org/publications/immigrant-access-to-health-insurance-nutrition-programs/>

The Hastings Center Project for Undocumented Immigrants & Access to Health Care
This database also includes a selection of recent literature on the emerging health consequences of immigration enforcement as it affects lawfully present immigrants, asylum seekers, and citizens in mixed-status households. (N. Berlinger, PhD and R. L. Zacharias (2019). <http://undocumentedpatients.org/issuebrief/undocumented-patients-in-the-local-safety-net-tools-for-teaching-learning-and-practice>

Federally funded primary care clinics for uninsured lower income patients
https://www.freeclinics.com/cta/north_carolina

Catholic Charities and local churches
This organization has offices throughout the state provides immigrant resources, counseling, social services and legal assistance to undocumented immigrants.
<https://www.catholiccharitiesraleigh.org/locations/>
<https://www.catholiccharitiesraleigh.org/raleigh/>



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NC and Federal Resources Continued

El Futuro in Durham
community mental health for Latinos w/ bilingual providers on sliding scale or Medicaid recipients
<https://elfuturo-nc.org/>

CWS Durham and Triangle
Multiple services to refugees and immigrants from all over the world
<https://cwsdu.org/>


North Carolina African Services Coalition
low-cost immigration legal assistance to any individual or family that needs the services
<https://africancommunity.org/nc-afsc/>

US Committee for Refugees and Immigrants—North Carolina chapter
Helps individuals and families make essential community connections to successfully integrate into our community
<https://refugees.org/field-office-north-carolina/>

Nation-based Consulates in the U.S.
can assist with funeral arrangements, travel to home country at end-of-life, and obtaining updated passports from the home country (which P1's may need as photo ID for applications)
<https://www.us-assessor-service-guide.com/us-embassy-and-consulate-list.html>

NC Council of Churches: Immigration Resources
links to organizations throughout the state related to psychosocial, legal and medical services for immigrants
<https://www.ncchurches.org/programs/immigration-link/>

American Civil Liberties Union (ACLU) of North Carolina
<http://www.acluofnc.org/>



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References


Migration Policy Institute (2020). **Profile of the Unauthorized NC Population**. [Online]. Available: <https://www.migrationpolicy.org/data/unauthorized-immigrant-population/state/NC/> [Accessed: 20-Feb-2020].

J. Hayes, B.A., M.S. (2019). **Finalized rule aims to keep families separated by slashing legal immigration and holding immigrants to a wealth test**, North Carolina Justice Center, [Online]. Available: <https://www.ncjustice.org/trump-administrations-public-charge-rule-an-improvement-on-previous-drafts-but-still-penalizes-low-wage-immigrants-and-their-families/>. [Accessed: 20-Feb, 2020].

S. Jaramillo, MD and D. Hui, MD, MSc (2016). **End of Life Care for Undocumented Immigrants with Advanced Cancer**, *Journal of Pain Symptom Management*, April, 51(4): 784-788.

US Citizenship and Immigration Services (2020). **Guidance on Evidence for Certain Types of Humanitarian or Significant Public Benefit Parole Requests**, [Online]. Available: <https://www.uscis.gov/humanitarian/humanitarian-parole/guidance-evidence-certain-types-humanitarian-or-significant-public-benefit-parole-requests>. [Accessed:20-Feb, 2020].

N. Berlinger, PhD and R. L. Zacharias (2019). **Resources for Teaching and Learning About immigrant Health Care in Health Professions Education**, *AMA Journal of Ethics*, January, Volume 21, Number 1: E50-57



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