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Hospice Access and Scope of Services for Undocumented Immigrants: A Clinician Survey

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Abstract

Objectives: To characterize clinician experiences of hospice access and scope of services for undocumented immigrants.

Background: The 10.5 million undocumented immigrants in the United States are not covered by Medicare's hospice benefit and are at high risk for being uninsured. Limited data are available regarding hospice services for this population.

Setting/Subjects: Two hundred ninety-four interdisciplinary palliative care clinicians from across the United States.

Measurements: Participants completed a web-based survey regarding hospice access and scope of services for undocumented immigrants in their location. We used simple frequencies to report clinician responses and chi-square analysis to evaluate associations between response and location. We performed rapid qualitative analysis of free-text responses to identify common limitations in scope of services.

Results: A majority of clinicians (68%) perceived that access to hospice was limited or unavailable for undocumented immigrants in their location, and among respondents who provided data regarding hospice scope, 38% reported that services provided to undocumented immigrants were limited compared to those provided to other patients. Reports of restricted access and scope varied by region, and those in large metropolitan areas were more likely to report restricted scope of care than those in smaller towns (43% vs. 28%; $p=0.03$). In our qualitative analysis of free-text responses, common limitations in hospice scope included reduced access to medications and equipment, inability to access inpatient hospice, inadequate translation services, reduced staffing, and restricted duration of services.

Conclusions: Undocumented immigrants may face barriers in accessing comprehensive hospice services. Public policy changes that improve access to hospice may improve end-of-life care for undocumented immigrants.

Keywords: health care access; health disparities; hospice; immigration; undocumented immigrants

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Introduction

An estimated 10.5 million undocumented immigrants live in the United States; this group includes both individuals who entered the country without authorization and those who are out of status, often because they have overstayed the time limitations of their visas.[1] The total undocumented immigrant population has declined in recent years, but the amount of time spent in the United States by individual undocumented immigrants has increased, with almost two-thirds of undocumented immigrants having been in the country more than 10 years.[1,2] As undocumented immigrants age, an increasing number may require medical care for serious or life-threatening illness.

Hospice care offers high-quality and cost-effective care for individuals with limited life expectancies.[3] The vast majority of hospice care is funded by Medicare; however, undocumented immigrants are not eligible for the Medicare Hospice Benefit due to their blanket exclusion from federally funded benefits, and most lack private health insurance that might cover hospice services.[4] Although the Affordable Care Act has expanded access to health care coverage to many individuals, undocumented immigrants represent the largest demographic group explicitly excluded from purchasing insurance on the government exchange.[5,6]

Clinicians have observed that undocumented immigrants may face significant barriers to hospice enrollment because of their immigration status, but current data are limited to case series and review articles.[7–10] Our prior nationwide survey of hospice agencies confirmed that nearly one-third of hospice agencies either limited or refused enrollment of undocumented immigrants.[11] However, these data described only hospice agencies' reported practices with respect to referrals.

To our knowledge, no data are available describing clinician observations of both access to hospice care for this population and the scope of services provided. In addition, clinicians' experiences in accessing hospice services for undocumented immigrants are likely to vary across the country given differences in undocumented population density and health care access,[12,13] and there is a lack of consolidated information describing the types of limitations undocumented immigrants face in obtaining appropriate end-of-life care. Therefore, the purpose of this study was to more broadly describe hospice access and scope of services for undocumented immigrants through a survey of clinicians from across the country.

Materials and Methods

Participants and setting

Data for this study were obtained through distribution of an online survey between November 2018 and March 2019. We recruited a convenience sample of clinicians from around the United States who were likely to care for undocumented immigrants at the end-of-life through e-mail and electronic message boards of the American Academy of Hospice and Palliative Medicine (AAHPM) and the Academy of Oncology Social Work (AOSW).

Survey administration

Organization members received an initial invitation to participate, followed by a reminder notice at one month. Compensation was not provided across the sample, but participants had the option of being enrolled in a drawing to receive one of twenty $50 gift cards in appreciation of their participation. The study was approved by the Duke University Health System's Institutional Review Board (Duke IRB Protocol No. 00079346).

Measure development

The survey tool was developed by the investigators (N.A.G., N.A.B., N.B., L.C., K.S.J.) to assess clinicians' experiences of (1) hospice access (availability of hospice services to undocumented immigrants) and (2) scope of hospice services provided for undocumented immigrants. Initial format for survey was adapted from a prior questionnaire regarding nephrologists' experiences in caring for undocumented immigrants with end-stage renal disease (ESRD).[14] All survey questions were reviewed by the research team for face validity and pilot tested by an interdisciplinary panel of five clinicians before the start of the study. The full survey is available in the Supplementary Data. Survey creation and distribution were performed using Qualtrics CoreXM web-based survey software (Qualtrics, Provo, UT).

Measures

Clinicians were asked to compare the availability of hospice services for undocumented immigrants to that of other seriously ill patients as ''similar,'' ''restricted'' or ''unavailable.'' We asked participants to identify usual funding sources for hospice care for undocumented patients from a list of potential options (state and local government, local hospice agency charity care [unreimbursed services], hospital or health system, or other). We asked clinicians to describe their impressions of scope of hospice services provided to undocumented immigrants in their location compared to those provided to other patients as ''similar'' or ''restricted'' in scope. In free text, we asked those who reported restricted scope of services to further clarify in what way they observed that services differed from those delivered to other patients.

We collected information regarding clinicians' discipline (physician, physician assistant, nurse practitioner, social work, and other), specialty, practice location (state and city size—large metropolitan, midsize city, small town, and rural), whether they had cared for undocumented immigrants in the prior year, and frequency of their awareness of patients' immigration status (always, sometimes, rarely, and never).

Data analyses

We used frequencies and percentages to describe survey items above. We used chi-square analyses to evaluate associations of city size and geographic location with hospice access and scope of services. For the purpose of chi-square analysis, responses that access was limited or unavailable were combined into a single category of ''limited.'' City sizes were grouped into large metropolitan areas versus smaller cities, and in analysis for associations with geographic location, states were grouped by U.S. census region (Midwest, Northeast, South, West). In calculating percentages and associations, we omitted responses, in which the participant stated that they ''did not know'' or ''did not wish to answer.''

Data analyses were performed using the statistical software GraphPad Prism version 8.2.0 (GraphPad, San Diego, CA). $p < 0.05$ was considered statistically significant.

To identify recurrent themes in the qualitative data obtained from clinicians' free-text responses regarding limitations in hospice scope, we performed a rapid thematic analysis informed by a modified Framework Method.[15] In our approach, an initial review of text responses was conducted to identify common thematic categories, and text responses were then reviewed independently by three reviewers (N.A.G., N.A.B., and K.S.J.), with verification of sorting, and identification of additional themes, followed by final discussion to identify discrepancies in sorting and reach consensus.

Results

Participants

Among the 391 respondents who opened the link to the survey and viewed the online consent, 346 (88.5%) proceeded to complete a portion of the survey questions. Fifty-two of these respondents did not provide information regarding hospice access and were excluded. These nonrespondents to the hospice access question did not differ by practice type, discipline, or city size from respondents but included a higher proportion of clinicians from the U.S. South (21.7% vs. 13.7%; $p = 0.02$). The final sample included 294 clinicians (75.2% completion rate among those who opened the survey link) who completed the full survey.

Among the 294 participants who completed the relevant portions of the survey, a majority of respondents (200 [68.0%]) were physicians (MD/DO), followed by social workers (53 [18.0%]), physician assistants, nurse practitioners (19 [6.5%]), and others (22 [7.5%]), including pharmacists, nurse specialists, and case managers (Table 1). Forty-three states and the District of Columbia were represented by respondents in the survey. Responses were well-distributed across the United States. with 83 (28.2%) from the U.S. South Census region, 78 (26.5%) from the West, 70 (23.8%) from the Midwest, and 63 (21.4%) from the Northeast.

The most frequent areas of practice reported (participants selected all that applied) were hospital-based palliative care (156 [53.1%]) and hospice (64 [21.8%]), with 48 (16.3%) reporting practice in clinical social work or case management, and 28 (9.5%) reporting work in hospital medicine; other areas of practice included outpatient general medicine, oncology, pediatrics, and outpatient palliative care.

The most frequent practice descriptors were ''academic or teaching health system'' (138 [46.9%]) and ''private health or hospital system'' (137 [46.6%]) with the remainder of responses, including ''state/local government hospital or health system'' and ''federal government hospital or health system.'' Most respondents practiced in large metropolitan areas (185 [62.9%]) or midsize cities (66 [22.4%]). The majority (251 [85.4%]) of respondents reported that they had cared for undocumented immigrants in the past year, and more than half reported that they were aware of the immigration status of their patients ''always'' or ''often'' (193 [65.7%]).

Hospice access and scope

Table 2 includes participants' responses describing access to hospice care and scope of services. The majority of respondents reported that access to hospice for undocumented immigrants was limited (188 [63.9%]) in their location compared to access for other patients, and a small minority (13 [4.4%]) noted that access was not available at all. The most frequent funding source for hospice access among undocumented immigrants reported by respondents was enrollment through hospice agency charity care (238 [81.0%]), followed by hospital or health system support (62 [21.1%]) with the remainder coming from state and local government programs or other sources.

Regarding scope of hospice services, 210 participants provided data concerning hospice practices for undocumented

Table 1. Characteristics of Survey Participants ($N = 294$)

Characteristic	n *(%)*
Discipline	
Physician	200 (68.0)
Social work	53 (18.0)
Nurse practitioner or physician assistant	19 (6.5)
Other	22 (7.5)
U.S. census region	
Midwest	70 (23.8)
Northeast	63 (21.4)
South	83 (28.2)
West	78 (26.5)
Practice location	
Large metropolitan	185 (62.9)
Midsize city	66 (22.4)
Small town	41 (13.9)
Rural	2 (0.7)
Practice type[a]	
Hospital-Based Palliative Care	156 (53.1)
Hospice	64 (21.8)
Clinical Social Work/Case Management	48 (16.3)
Hospital Medicine	28 (9.5)
Outpatient/Community Palliative Care	20 (6.8)
Oncology	14 (4.8)
Outpatient General/Family Medicine	12 (4.1)
Other	13 (4.4)
Practice site characteristics[a]	
Academic Teaching Hospital/Health System	138 (46.9)
Private Hospital/Health System	137 (46.6)
State or Local Government Health System	49 (16.7)
Federal Government Health System	9 (3.1)
Practice site financial structure[a]	
Not for profit	249 (84.7)
For profit	30 (10.2)
Government run	34 (11.6)
Provider awareness of immigration status	
Always	56 (19.1)
Often	137 (46.6)
Sometimes	62 (21.1)
Rarely	31 (10.5)
Never	8 (2.7)
Care for undocumented immigrants in preceding 12 months	
Yes	251 (85.4)
No	17 (5.8)
I don't know	26 (8.8)

[a] Respondents selected all descriptors that applied; percent totals >100%.

TABLE 2. HOSPICE ACCESS, FUNDING, AND SCOPE OF SERVICES FOR UNDOCUMENTED IMMIGRANTS

Access to hospice: How would you describe the availability of hospice services for undocumented patients in your location of practice?	
Response	n *(%)*
Availability of services is similar to or equivalent to that of other patients	93 (31.6)
Services are available but there is less access for undocumented patients than other patients	188 (63.9)
Services are not available at all	13 (4.4)
Funding source: If undocumented patients in your location are able to access hospice services, through what support are those services available?	
Response	n *(%)*[a]
State government programs	47 (16.0)
Local government programs	13 (4.4)
Hospital or health system programs	62 (21.1)
Charity care from local hospice agencies	238 (81.0)
Other	8 (2.7)
Scope of services: For undocumented patients who ARE able to access hospice services in your area, how do those services compare with those provided to U.S. citizens?	
Response	*Responses (%)*[b]
Care is the same	131 (62.4)
Care is restricted or limited in scope	79 (37.6)

[a] Respondents selected all descriptors that applied; percent totals >100%.

[b] Total excludes responses left blank or marked “I don’t know,” $n=210$.

TABLE 3. THEMES WITH ILLUSTRATIVE QUOTES FROM OPEN-ENDED RESPONSES REGARDING SCOPE OF HOSPICE SERVICES

Theme	*Illustrative quotes*
Restrictions in provision of medications and equipment	“Patients have access to service providers but no coverage for meds or procedures.” (Physician, academic/teaching hospital, South) “Patients obtain medications and sometimes DME (Durable Medical Equipment) through our hospital system …, not covered through hospice as it normally would be.” (Physician, academic/teaching hospital, Midwest) “Hospice may pay for an abbreviated range of medications.” (Nurse Practitioner, academic/teaching hospital, West)
Lack of appropriate language and translation services	“Ancillary hospice services are often limited due to language barriers.” (Outpatient social worker, academic/teaching hospital, South) “There is only one hospice in our area that has a Spanish-speaking team, so I tend to refer to this hospice. Thus, our Spanish-speaking undocumented patients rarely have the same choices …” (Social worker, private hospital, West) “Ancillary services are limited due to language barrier.” (Social worker, academic/teaching hospital, South)
Reduced staff visits or reduced access to the full interdisciplinary team	“… hospice agencies state that they will only provide one visit per week until death is imminent.” (Social worker, academic/teaching hospital, Midwest) “They receive fewer home attendant hours, fewer visits from all members of team, and less coverage of equipment and medication.” (Physician, academic/teaching hospital, Northeast) “… minimal services, often only nurse visits.” (Physician, academic/teaching hospital, West)
Restrictions in setting of hospice care	“It’s rare for undocumented immigrants to be able to stay in the hospice inpatient unit, as they are not inclined to offer charity beds. Sometimes this means patients have to stay in hospital.” (Physician, academic/teaching hospital, Midwest) “It’s difficult to provide inpatient hospice … only … home hospice services via charity.” (Physician, academic/teaching hospital, Northeast) “They are usually not given access to GIP [general inpatient] or crisis care.…” (Physician, private hospital system, South)

(*continued*)

patients who were enrolled in hospice. Of those, 131 (62.4%) reported that in their location, hospice services for undocumented patients were the same as for other patients. However, over one-third (79 [37.6%]) noted that hospice services for undocumented immigrants were restricted or limited in scope compared to services provided for other patients. Among clinicians in our sample who reported hospice as at least one of the settings where they worked ($N=64$), perceptions of access to care did not differ significantly from other respondents; however, compared to clinicians who did not work in hospice, providers who worked in hospice were more likely to report that hospice services for undocumented immigrants were similar in scope to those for other patients. (77.8% vs. 57.1%; $p=0.007$).

In our thematic analysis of comments from the 166 respondents who completed the free-text field regarding their experience of restrictions in scope of services, five common themes emerged (Table 3). These included (1) restrictions in the setting where hospice care could be offered, (2) limited provision of medications or equipment from hospice agencies, (3) lack of appropriate translation services, (4) reduced hospice staff visits or reduced access to the full interdisciplinary team, and (5) reduced duration of hospice services provided. Representative comments were selected for each theme and are included in Table 3.

In chi-square analysis, hospice access was associated with census region, with a lower proportion of respondents from the U.S. South indicating that they believed that access was restricted (limited or not available) for undocumented

Table 3. (Continued)

Theme	*Illustrative quotes*
Reduced duration of service or services limited to imminently dying patients	"Undocumented patients have to be clearly terminal … prognosis of 2 weeks. They cannot have a borderline diagnosis or prognosis." (Physician, academic/teaching hospital, West) "Most of the time, they are declined … However very rarely if they are close to dying, free hospice is given for inpatient hospice." (Physician, academic/teaching hospital, West) "… less early access or expensive care is offered." (Physician, private hospital system, Northeast)

patients compared to those in the West, Midwest, and Northeast (53% vs. 73%, 74%, and 76%, respectively; $p = 0.005$). Access to hospice services was not significantly associated with city size.

Scope of services was also associated with geographical region, with a smaller proportion of respondents in the South and Midwest reporting that scope of services was limited, compared with the Northeast and West (33% and 26% vs. 56% and 40%, respectively; $p = 0.02$). Perceptions of scope of services were also associated with city size, with respondents in smaller cities and rural areas less frequently reporting that scope of services was limited compared with those in large metropolitan areas (28% vs. 43%; $p = 0.03$).

Discussion

In this national survey describing health care clinicians' perceptions of access to and scope of hospice services for undocumented immigrants, a majority of clinicians in our sample reported limitations in access to hospice care for undocumented immigrants and more than a third reported that the hospice care provided was reduced in scope when compared to that offered to other patients in their location. Potential differences in scope of services cited by respondents included limitations in setting of hospice care, reduced duration of services, restricted provision of medications or equipment, reduced access to personnel, and inadequate language resources. Among our sample, clinicians' perceived limitations in access and scope varied by region, and limitations in scope were more commonly reported by clinicians in large metropolitan areas compared with smaller cities. Our findings suggest that access and scope may be highly variable depending upon local differences in health care practices or demand. These results have important implications for policy changes, which may improve end-of-life care for this vulnerable population.

Clinicians' observations that access to hospice care may be limited for many undocumented immigrants aligns with other work documenting barriers in access to health care for this population across the health care continuum in the United States. Prior studies suggest that undocumented immigrants are less likely to have physician visits or a usual site of medical care, less likely to have appropriate health screening tests, and more likely to present with later stage illness at the time of diagnosis.[16–21] Undocumented immigrants may additionally avoid presenting for medical care at all due to concerns about their residence status and deportation, and recent federal immigration policy changes may have further deterred participation in public programs such as the Children's Health Insurance Plan (CHIP) among children of undocumented immigrants.[22–25]

Based on the results of this study and our prior survey of hospice agencies,[11] challenges in obtaining needed health services can potentially persist even to the end of life, as many undocumented immigrants may not be able to access the comprehensive set of services provided by hospice. These disparities in end-of-life care for undocumented immigrants faced with life-limiting illness may be even further exacerbated by difficulty accessing usual health services in the context of the COVID-19 pandemic.[26]

The limitations participants in our sample reported in access and scope of hospice services for undocumented immigrants may reflect the financial challenges involved in providing care for a patient population not covered by Medicare's hospice benefit and at high risk for being uninsured. Given that charity care from individual hospice agencies was cited as the most common source of hospice access for undocumented immigrants, limiting enrollment of undocumented patients or restricting expenditures such as staff visits or equipment may be a necessary measure for agencies to manage the financial strain of unreimbursed care.

Such limitations in hospice services might be expected to play a larger role in places where the undocumented population is high, such as in large metropolitan areas (where 6 out of 10 undocumented patients reside).[12] This potential for demand-driven rationing could explain the association we saw between large metropolitan areas and participants' reports of restricted scope of care. While it is difficult to make generalizations about access in various regions of the country based on clinician experiences in our sample, our findings raise the possibility that services for undocumented patients may be most limited in places where the need is greatest.

The findings of this study and others suggest a need for new strategies and policies which address barriers to health care for undocumented patients throughout the illness trajectory. Some states, such as California, which recently considered expansion of state Medicaid access to young-adult undocumented immigrants, are actively seeking ways to broaden health care services for undocumented immigrants.[27] Cities, including Boston, New York, and San Francisco, have enacted local measures to expand health care access to include extended services (beyond emergency stabilization) for undocumented patients in instances of chronic or catastrophic illness.[28]

In one example of such expansion several states now offer funding for scheduled hemodialysis for undocumented patients with ESRD, rather than limiting benefits to emergency dialysis only.[29,30] This has been shown to reduce overall costs of care, decrease mortality, improve patient satisfaction, and reduce utilization of emergency room facilities for undocumented patients with ESRD.[31,32] As hospice has previously been shown to reduce hospitalization, enhance quality of life, and save costs,[3] public policies which ensure consistent access to hospice care might offer similar improvements in costs and care for undocumented patients facing terminal illness when compared to the alternative of using emergency department care and acute hospitalization to meet end-of-life needs. Some respondents reported that their state government programs such as Medicaid covered hospice for undocumented immigrants. Future research should examine variation across states in Medicaid coverage for hospice care for undocumented patients and determine the effect of such policies on costs and quality of care.

For those undocumented patients with earlier stage serious illness, ensuring access to outpatient palliative care services, which have the potential to reduce costs and improve care,[33,34] could further improve quality of life and promote cost efficiency across the continuum of serious illness.

This study has several limitations. As no standardized system of observing or tracking immigration status exists in most health systems, we relied on clinicians' reports of their experiences and observations, which may have led to an over- or underestimate of limitations in access and scope of hospice services for undocumented patients. In particular, recall bias from particularly challenging cases could cause clinicians to overestimate the burden of restriction. In addition, small towns and rural areas, where clinician experiences with access could be significantly different than that in larger cities, were underrepresented among survey participants.

While clinician reports of variations in access and scope based on U.S. census region reached statistical significance, in light of small sample size and higher exclusion rate for responses from the U.S. South, it is difficult to make broad regional generalizations about clinician experiences with availability and scope based on geography. These findings should be explored in other studies. Finally, while we attempted to address possible response bias through characterization of those who chose not to answer the questions regarding access, it is also possible that those who have never observed issues with limited access might have chosen not to participate, which could have inflated our estimates of restrictions based on participant responses. Despite limitations in sample and reliance on recall, our clinician responses mirrored our prior findings from a survey of hospice providers that hospice agencies often limit enrollment[11] and further add to the evidence that access to hospice care may be restricted for undocumented patients.

Conclusion

A majority of clinicians surveyed across the United States perceived that undocumented immigrants face challenges in obtaining access to comprehensive hospice support. With the aging of the undocumented immigrant population, the need for hospice services in this population is likely to grow in coming years. The current system of reliance on unreimbursed charity care from individual hospice agencies to serve undocumented immigrants places difficult burdens on those agencies and may further drive limitations in access or scope of services provided. Until broader public policy solutions facilitating hospice coverage are available, collaboration between hospice agencies and health systems is crucial to ensuring access to hospice care for this population.

Additional research is needed to examine variation in costs, resource utilization, quality of care, and other patient/family reported outcomes for undocumented immigrants with unrestricted access to hospice care compared to those for whom such services are not available. Such data may bolster the argument for expanded access to hospice care for this population by demonstrating improved efficiency of health care delivery. However, for now, efforts to address barriers in care for undocumented immigrants with advanced illness will likely continue to be complicated by the precarious position of this issue at the intersection of simultaneous controversies regarding health care policy and immigration.

Authors' Contributions

All authors for this study meet the authorship requirements as stated in the Uniform Requirements for Manuscripts Submitted to Biomedical Journals.

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Supplementary Material

Supplementary Data

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