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Abstract

Background: People experiencing homelessness have limited access to palliative care support despite high levels of ill health and premature mortality. Most research exploring these challenges in the United Kingdom has focused on people living in hostels or temporary accommodation. People with uncertain or restricted immigration status are often unable to access this accommodation due to lack of entitlement to benefits. There is little research about the experiences of those in the United Kingdom who cannot access hostels or temporary accommodation due to restricted or uncertain immigration status with regards to palliative and end-of-life care access.

Aim: To explore the barriers to palliative and end-of-life care access for people with uncertain or restricted immigration status, who are experiencing homelessness and have advanced ill health, and the experiences of UK hospices of supporting people in this situation.

Design: A multi-method cross-sectional study.

Setting/participants: An online survey for hospice staff followed by online focus groups with staff from inclusion health, homelessness and palliative care services, charities and interviews with people experiencing homelessness.

Results: Fifty hospice staff responded to the online survey and 17 people participated in focus groups and interviews (focus groups: $n = 10$; interviews: $n = 7$). The survey demonstrated how hospices are not currently supporting many people with restricted or uncertain immigration status who are homeless and that hospice staff have received limited training around eligibility for entitlements or National Health Service (NHS) care. Interview and focus group data demonstrated high levels of unmet need. Reasons for this included a lack of consistency around eligibility for support from local authorities, issues relating to NHS charging, and mistrust and limited knowledge of the UK health and social care system. These barriers leave many people unable to access care toward the end of their lives.

Conclusion: To advocate for and provide compassionate palliative and end-of-life care for people with uncertain immigration status, there is need for more legal literacy, with training around people's entitlement to care and support, as well as easier access to specialist legal advice.

Plain language summary

Palliative care, homelessness and restricted or uncertain immigration status

Most research from the UK about access to support at the end of life for people who are homeless has looked at the experiences of people who are staying in hostels or temporary accommodation. People that are not UK nationals are not entitled to the benefit which pays for hostel or temporary accommodation. There is a group of people in the UK who are very unwell, who are homeless and are not able to access hostel accommodation due to their immigration status. This project explored the experiences of this group around access to palliative care. We spoke to professionals from health and social care services, charities and local councils and people who are in this situation themselves. Hospice staff

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were also surveyed to see if they had experience of supporting people in this situation. The survey showed that hospices are not currently supporting many people with restricted or uncertain immigration status who are homeless, and that they have limited training around supporting people in this situation. In the interviews and focus groups, opinions were heard about challenges to palliative care support for people with uncertain or restricted immigration status who were experiencing homelessness. Professionals described how it can be hard to obtain support from local authorities, and also understanding rules about who has to pay to receive NHS care. People with uncertain or restricted immigration status who were also homeless did not always know how to access the UK health and social care system and had negative experiences of doing so in the past. As a result, many people are unable to access care towards the end of their lives. To provide compassionate palliative and end-of-life care for people with uncertain immigration status, there is need for more legal literacy, with training around people's entitlement to care and support, as well as easier access to specialist legal advice.

Keywords: homelessness, hospices, palliative care, qualitative, survey

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Introduction

Health care from the National Health Service (NHS) is free for people who are ordinarily resident in the United Kingdom. For some non-UK nationals access to some aspects of NHS care (such as some secondary care) is chargeable. In England, primary care and emergency care services are free for everyone, irrespective of immigration status.[1] In 2015, rules governing the charging of 'overseas visitors' accessing NHS services in England were changed, with the intention of ensuring that the NHS did not lose income by providing care to those not eligible for free treatment.[2–4] Overseas visitors could be charged up to 150% of the cost of NHS services, and additional powers came into play for Hospital Trusts to make and recover charges from chargeable patients. In 2017, these rules were updated placing a statutory duty on Trusts to charge patients upfront for non-urgent care, and to record patients' eligibility for free treatment.

Despite this, safeguards do exist, and for non-UK nationals who are not entitled to free NHS care, treatment can be given without payment in advance if it is deemed 'urgent' or 'immediately necessary', although patients may still be charged or billed retrospectively. Only clinicians can make an assessment as to whether treatment is immediately necessary, urgent or non-urgent. 'Urgent' treatment is that which, although not immediately necessary, cannot wait until the person can be reasonably expected to leave the United Kingdom. If the person is unlikely to leave the United Kingdom for some time (which will be the case for some undocumented migrants), treatment which clinicians might otherwise consider non-urgent (e.g. certain types of elective surgery) is more likely to be considered by them as urgent. With regards to access to palliative care, the interpretation of whether this could be considered urgent or necessary is complicated. Care provided by hospices is not chargeable, as it is usually only partially funded by the NHS, but palliative care in a secondary NHS care may be.

In this paper 'restricted immigration status' includes people who have no legal status such as undocumented migrants (e.g. as visa overstayers, people whose asylum applications have been rejected as well as some EU nationals without settled status). None of these groups have access to public funds or benefits. We refer to people with 'uncertain or restricted' immigration status, because often without thorough legal investigation, it may be unclear what someone's actual immigration status is. Some people have leave to remain in the United Kingdom, but do not have entitlement to public funds (no recourse to public funds – NRPF).

People with restricted or uncertain immigration status might be particularly vulnerable to homelessness as their immigration status means they frequently lack entitlement to benefits (have NRPF) and are not owed a statutory housing duty by the local authority. In addition to a potentially insecure financial situation, they may experience societal stigma and discrimination, have limited support networks to draw upon and have difficulties navigating UK systems and services.[5–7] Furthermore, they may have been exposed to traumatic experiences, domestic violence, war or torture in their homeland or when fleeing to the United Kingdom.[8,9]

In 2020, a large proportion of people sleeping on the streets in England were found to be not UK nationals, or their nationality was unknown.[10] There is growing evidence that the scale and the support needs of this population are increasing.[5] Doctors of the World completed an audit of people accessing their specialist casework support and legal advice due to being refused NHS care based on their immigration status. Almost everyone included in the audit (93%), was destitute, meaning that they did not have adequate accommodation or funds to meet their basic needs.[11]

Even though people with restricted immigration status may have NRPF, support through adult social care, provided under the Care Act, is not a public fund. This means adult social care may have a duty to provide support (housing and basic financial support) for someone, if they are destitute and are deemed to have care and support needs (eligible under the Care Act 2014). The Care Act is seen by the Home Office as a justification for the NRPF status, as, in principle, it should ensure the most vulnerable are protected. In practice, this is not always the case.

Homelessness is associated with high rates of long-term health conditions compared with the housed population.[12] In England in 2022, the mean age at death of people who were street homeless or in emergency shelters was 45.9 years for men and 41.6 years for women.[13] People experiencing homelessness rarely have access to palliative and end-of-life care, suggesting that their symptoms may be unmanaged and their deaths unsupported.[14,15]

Previous work has identified a range of factors fuelling inequity of access to palliative and end-of-life care support between people experiencing homelessness and housed population.[14,16] As healthcare is often only accessed in emergency situations, opportunities for planned support and the identification of palliative care need in this population are few. In addition, people experiencing homelessness often do not fit the profile of a ‘typical’ referral to palliative care.[17] Within many community or homelessness services there is also a lack of knowledge and understanding about palliative care and how it could support people with advanced ill health.[18]

The majority of research exploring this in the United Kingdom has focused on the experiences for people living in homeless hostels.[14,16,18,19] In the United Kingdom, hostels are a form of ‘supported housing’ with a remit to accommodate people who have support needs, such as substance use disorder or mental health difficulties, to move out of homelessness.[20–22] The primary aim of hostels is not to facilitate access to health and social care, yet it is often through a connection with the hostel that people experiencing homelessness are able to access basic health and social care support.

Most non-UK nationals cannot stay in hostels as they are not entitled to the benefits needed to pay for this. Therefore, further challenges to accessing support for people with restricted or uncertain eligibility for benefits who are homeless and very unwell are anticipated.

This project sought to explore the challenges to palliative and end-of-life care access for people with uncertain or restricted immigration status, who are experiencing homelessness.

Methods

A multi-method cross-sectional study was conducted involving a survey for hospice staff, focus groups and interviews with people with uncertain or restricted immigration status who had advanced ill health and were experiencing homelessness and online focus groups with staff that support them from a range of professional groups.

Hostel staff survey

Sample

The survey was open to any clinical staff working in a UK-based hospice.

Recruitment

The survey for hospice staff was circulated *via* newsletters aimed at palliative care professionals, through contacting individual hospices, *via* social media, and *via* conference presentations attended by palliative care professionals given by the authors.

Data collection

The online survey was developed using Microsoft Forms. Survey questions were developed by the research team after consultation with organizations specializing in supporting people with restricted or uncertain immigration status. Respondents were asked short demographic questions about their gender, ethnicity, job role, the hospice in which they worked and the services their hospice offers. They were then asked closed and open-ended questions about the following:

- their experiences of supporting people with uncertain or restricted eligibility for benefits who were unwell and/or experiencing homelessness
- their views on barriers to supporting people in this situation
- knowledge about NHS charging and its exemptions and about potential support under the Care Act
- training received about supporting people with uncertain or restricted eligibility for benefits
- awareness of where to find support for people in this situation

The survey was open between January and May 2022.

Data analysis

Quantitative data from the survey were analyzed using descriptive statistics within Microsoft Excel by BH. Qualitative open text responses were analyzed using thematic analysis by BH and discussed with the research team to create the final themes in the report. Data from the survey was analyzed separately from data gathered in the focus group and interviews.

Focus groups

Sample

Purposive sampling was used to select individuals that had experience of supporting people with uncertain or restricted immigration status, who had advanced ill health and were experiencing homelessness. They could come from any of the following professional backgrounds: health, homelessness, social care, palliative care, local authorities.

Recruitment

Professionals were recruited for the focus group *via* the research team's existing professional connections, *via* the Faculty for Homeless and Inclusion Health newsletter, and social media.

Data collection

Three focus groups and follow-ups were held online between January and May 2022. A topic guide was developed by the study team to explore professional's experiences of supporting people with restricted or uncertain immigration status who had advanced ill health and were experiencing homelessness to access health care services or support. Two focus groups were led by CS and a third by AB, all were supported by BH. Reflexive notes and peer debriefing were used following each focus group to mitigate risk of bias. Focus groups lasted up to 1 h and were conducted and recorded on Microsoft Teams. Some professionals attended interviews rather than focus groups due to scheduling conflicts and challenges.

Interviews with people with lived experience

Sample

To be eligible for the interviews, a person would need to have lived experience of homelessness, uncertain or restricted immigration status, and poor health.

Recruitment

People with uncertain or restricted immigration status, whose health was poor and who had experience of homelessness were recruited *via* the attendees of the focus groups for professionals. Focus group attendees were provided with an information sheet that they could discuss or share with people that they felt may be interested in participating. They also supported a connection with the research team, so that the researchers could discuss the study further with the potential participant and collect informed consent for participation.

Data collection

Interviews with people with current experience of uncertain or restricted immigration status, poor health, and homelessness were also conducted online and were also attended by the professional that identified them as a potential participant in the research, if requested. A topic guide was developed which was used to explore experiences of accessing services that could support their health needs. Interviews were conducted by CS.

Data analysis

Focus group and interview recordings were transcribed verbatim, anonymized and entered in NVivo for analysis using reflexive thematic analysis.[23] This involved familiarization with the data by reading the transcripts to gain a sense of the experiences shared. Line by line coding of each transcript was undertaken to identify initial codes in the data which were then grouped into initial themes. These themes were reviewed, revised, and combined where necessary to provide the final themes reported in this paper which were refined through critical dialogue with all authors. Transcripts were independently analyzed by MY and BH, both female researchers, experienced in qualitative research. Data were reported in line with the Consolidated Criteria for Reporting Qualitative Research (COREQ) guidelines.[24]

Ethical considerations

The research team is experienced in conducting research with people experiencing homelessness, three are clinicians (two specializing in inclusion health), the fourth is a health psychologist. The importance of trust and anonymity were paramount in this research and individuals with lived experience were recruited *via* professionals that were known to them, and who had themselves participated in the research. All participants provided written consent prior to data collection. Participants were reminded that participation was voluntary and all data would remain anonymous.

Patient and public involvement

We have consulted organizations that support people with restricted or uncertain immigration status throughout the course of this project. Their support has been invaluable in shaping the questionnaire and the topic guide and we are very grateful for their input and the changes made to this study as a result.

Results

Hospice survey findings

A total of 50 hospice staff completed the survey. Most respondents were female ($n=44$, 88%) and White British ($n=34$, 68%). The most common professional group of respondents was registered nurses ($n=16$, 32%), followed by clinical nurse specialists ($n=8$, 16%). Almost half of respondents had more than 10 years' experience of working in palliative and end-of-life care ($n=23$, 46%). Most respondents were from hospices in England ($n=40$, 80%) but the other nations were represented: Northern Ireland ($n=6$, 12%), Wales ($n=1$, 2%), and Scotland ($n=3$, 6%).

Experiences of supporting people experiencing homelessness who may have NRPF

Just over a quarter of hospice staff reported supporting at least one person experiencing homelessness who was sleeping rough in the past 2 years ($n=13$, 26%). A greater number had supported someone experiencing homelessness who was living in a hostel or temporary accommodation ($n=36$, 72%) or sofa surfing ($n=36$, 72%). Smaller percentages of hospice staff reported supporting people who they believed had NRPF ($n=4$, 8%). Half of the sample responded that they did not know whether any of the patients they supported had NRPF.

Discussions of immigration status in hospice settings

Over half of hospice staff ($n=26$, 52%) did not routinely discuss immigration status with service users. Almost a third rarely explored this ($n=15$, 30%); ($n=1$, 2%) always explored this, and ($n=8$, 16%) did not know whether this was routinely explored. Similar patterns can be seen around exploring entitlement to NHS care. More hospice staff asked patients about their housing situation and entitlements to certain benefits (see Table 1). It was more common to enquire about a patient's housing status, although over a quarter of respondents ($n=14$, 28%) reported rarely or never asking about this.

Access to training about eligibility for benefits or immigration status for hospice staff

Ninety-two percent of hospice staff ($n=46$) reported never having received any training about entitlements or the responsibilities of adult social

Table 1. Question: To the best of your knowledge, when you have a referral for a new patient, are they asked about any of the following?

Are new patients asked about the following	Always (n, %)	Very often (n, %)	Sometimes (n, %)	Rarely (n, %)	Never (n, %)	Don't know (n, %)
Their housing situation	10 (20%)	8 (16%)	12 (24%)	12 (24%)	2 (4%)	6 (12%)
Their immigration status	0	0	1 (2%)	15 (30%)	26 (52%)	8 (16%)
Their entitlement to universal credit/housing benefits	2 (4%)	3 (6%)	8 (16%)	10 (20%)	20 (40%)	7 (14%)
Their entitlement to NHS care	0	1 (2%)	4 (8%)	11 (22%)	26 (52%)	8 (16%)

NHS, National Health Service.

care services for people with uncertain or restricted immigration status. The majority (n=41, 82%) did not feel confident in accessing advice relating to restricted or uncertain immigration status for people who were homeless and very unwell. Only 6 (13%) correctly identified that it is a hospital clinician's decision whether care could be provided without payment in advance to someone without eligibility for free NHS care. Over three quarters of respondents (n=34, 76%) selected 'don't know' in response to this question.

Challenges to supporting people with restricted or uncertain immigration status

Hospice staff described practical barriers and receiving a low number of referrals, if any to support people with restricted or uncertain immigration status.

Limited referrals to hospices were thought to be linked to limited awareness from both people with lived experience and those involved in their care regarding the potential role that hospices could play.

Where referrals were received, practical issues encountered included language barriers, access issues linked to digital exclusion, and transportation issues linked to limited personal funds. Despite challenges, examples of how hospices have provided support for people in this situation were also described and are outlined in Table 2.

Findings from focus groups and interviews

Participants

Seventeen people with a range of experiences were recruited to focus groups and interviews (focus groups: n=10; interviews; n=7). Among participants, the following professional groups were represented: frontline homelessness staff (n=3), inclusion health staff (n=7, mental health, social worker, GP, and nurses), government employees involved in immigration and advice (n=3), legal immigration advisor (n=1), people with lived experience (n=2), hospice staff (n=1).

Participants described how inflexible, complicated, and fragmented services and systems blocked the provision of high-quality care and support for people with restricted or uncertain immigration status who were homeless and had advanced ill health. Findings are discussed under three separate, but related themes. The first theme related to consistency around eligibility for support from local authorities. The second theme related to issues around NHS care. The final theme explores the fear, mistrust, and limited knowledge of the UK health and social care system among people with uncertain or restricted immigration status which results in late presentation to care services and barriers to palliative care support.

Challenges around eligibility for support from local authorities

High and varied thresholds for support from local authorities. Despite potential support (including with accommodation) under the Care Act for people who are destitute and have care and support needs, from the qualitative data it was clear that thresholds for what constitutes 'care and support needs' vary greatly between different local authorities. Participants provided examples of people who were extremely unwell but were not deemed to have care needs, leaving them ineligible for local authority support.

Table 2. Types of support provided by hospices to people with restricted or uncertain immigration status, who were experiencing homelessness and who had advanced ill health.

Type of support provided	Examples
Practical support	Access to clothes, bedding, mobile phones, food banks, and support with transport to appointments
Referral to other services	Including immigration charities, legal advice, district nurses, and social services
Support with medical issues	Supporting people to register with different GP practices, arranging COVID tests, and getting prescriptions delivered to local pharmacies
Advocacy	Attending multi-agency meetings on the person's behalf, challenging decisions around COVID housing placements, following up with consultants regarding medical appointments, requesting advocates on the person's behalf, and supporting care act assessments

GP, general practitioner.

> Most have been receiving [NHS] treatment for their terminal diagnosis. The issue has been more around local authorities and social services. . .. pushing for humanitarian reasons for people to be housed, has been a big barrier. One individual was a rough sleeper. Sadly, he passed away. Social services kept pushing back and said that he didn't meet the threshold for their care needs, and he was rough sleeping with a terminal diagnosis of cancer. . .. (Inclusion health hospital nurse)

Interpreting and understanding legislation and entitlements. Participants also highlighted how the Care Act was not designed to support people with uncertain or restricted immigration status, who are homeless and who had palliative care needs. As such, eligibility for support from local authorities was not always clear cut and could be open to interpretation.

> The bar has been set high, but. . . if someone was recognized as having care needs. . . we would view that as enough to be able to step in and provide accommodation. You [a local authority] can exercise your power to do that [provide accommodation, even] if they don't meet care act criteria. . .There is flexibility due to the discretionary power. If someone is end of life, I think that would be seen as enough. But that's not always the case, it's not always clear cut. (Local council employee)

The complexity of legislation and entitlements to support from local authorities (including accommodation and subsistence) caused barriers to treatment and support for people with palliative and end-of-life care needs, whose health was deteriorating. Some people have leave to remain in the United Kingdom, but do not have entitlement to public funds. One inclusion health GP described the complexities within the system and the discretionary nature of some decisions:

> There's no quick fix unless you can do a 'change of condition' [i.e. removal of their no recourse to public funds status], but they need to be on a particular route [within the immigration system] in the first place. . .You can make an application on human rights and compassionate grounds and then it will be the home office's discretion whether that will be granted. You would need a good immigration advisor. . . it takes time. For people with severe care needs. . . the Home Office do have discretion to grant leave. . .. (Inclusion health GP)

As indicated in the previous quote, challenges around interpreting different pieces of legislation were common, with many staff feeling that they needed specialist advice to navigate processes. This process was often lengthy, and for people with advanced ill health, access to care and support was often time sensitive. However, access to specialist legal advice for both services supporting people in this situation and the individuals themselves was limited.

> Access to advice is almost nonexistent anyway. Access to immigration advice is hard, but harder with the practicalities of someone very ill, in hospital and has [mental] capacity issues. That's a real barrier. You want to get access and services sorted,

> so they are not worrying about that for the last months of their life. (Inclusion health nurse)

Even with access to the right knowledge and expertise, the need for constant advocacy to secure support takes much time, resource, and energy. It could be emotionally draining and taking a toll on everyone involved.

> There needs to be enough of you as a team to support each other. . .. You need time and knowledge. You also need the backup and support of colleagues to give you energy and resolve to support each other and keep going. With consistent work we will get further, but there are many barriers in place to try and limit access to services. (Inclusion health nurse working in a hospital)

Lengthy assessment periods. Participants described lengthy assessment processes regarding eligibility for local authority support. Without swift decisions people with uncertain eligibility were either waiting in hospital beds longer than medically necessary, were at risk of being discharged without the necessary support being in place or were not able to receive necessary treatment because of the lack of a suitable discharge destination. In some cases, this meant that necessary treatment was withheld. This quote from a charity representative describes the experiences of one man in his 40s who had NRPF, was destitute and had bowel cancer. He had just had an operation to remove a tumor but had been deemed by local authority to not meet the threshold for support with accommodation due to not having care and support needs.

> Without follow-up radiotherapy there was a 50% chance of the cancer recurring. They said they couldn't start the treatment because he didn't have an address and it was outpatient treatment. But then he was never discharged from hospital because there was nowhere for him to go. **In the end he'd stayed in the hospital so long he could have had the whole cycle of treatment. It was stupid**. He needed lots of medical supplies and stuff like that, so to me, even though he didn't need anyone to help him, that's a care need, isn't it? It was awful. (Inclusion health social worker)

Clearly the absence of suitable accommodation can have a major impact upon a person's ability to adhere to treatment and their overall health.

> We had one individual who needed a lot of fluid and special nutritional fluid that he has to feed through a tube into his stomach. He wouldn't be able to store that on the street. Managing their condition, which otherwise would dramatically deteriorate, is hard on the street. I think even that wasn't sufficient to trigger that duty [by local authority]. I think the provision just isn't there. (Inclusion health GP)

Issues relating to NHS care

In addition to challenges stemming from uncertainty about eligibility for support from local authorities, barriers related to challenges in accessing NHS support were also reported.

Pressured and limited resources. Demands on the NHS are growing, and pressure is building to reduce lengthy waiting lists. This translates into increasing pressure to discharge. Participants felt this pressure negatively impacted the ability of services to take a person-centered approach to care, particularly for those to whom the provision of care may be complicated.

> The pressure to discharge astounded me. I've never experienced anything like it my life. Holistic healthcare's just a thing of the past. . . What's going to happen when I discharge this guy? Within the next 24 hours he's going to be in another hospital somewhere. It's like, well, it won't be here, hopefully. (Inclusion health GP working within a hospital team)

Participants described how shrinking teams and inclusion health services within the NHS were resulting in a loss of expertise and connections within services. This reduced capacity hindered health care professionals' ability to advocate for the housing support from the local authority that was sometimes required for a patient to receive treatment. The cyclical nature of these challenges was clearly described by participants. This resulted in challenges to receiving quality care.

> There was only one social worker in the whole of the hospital at that point, so, that automatically caused a huge delay to them being discharged anyway. That often caused friction with the ward because of the delay and the fact we had documented that in the notes and once it was there, you couldn't take it back, they became immediately aware that meant that person was going to be on the ward with them for quite some time, based on the delay from the social worker. (Inclusion health hospital nurse)

Issues related to NHS charging: Variation in health care professionals' knowledge, actions, and attitudes. Despite the fact that, everyone is entitled to primary care in England, participants shared experiences of people being denied access.

> People are just declined. . ..with the assumption they had no right to register with primary care. When we know, anybody has a right to register with primary care, it is just heinous. So, yes, I would definitely say denial of care in primary care. (Inclusion health GP)

There was often confusion and complexity around when someone would be required to pay upfront for care and this could often result in dangerous delays in treatment. Participants described how, among other factors, an individual or teams' awareness of entitlements to care and their opinion of the urgency of that care could have a huge impact on the experience of patients with advanced ill health.

> We supported someone who had cancer which resulted in the life changing surgery. GP records showed they approached their GP a year before their cancer diagnosis about a growth in their throat and was referred for a biopsy, but the team responsible for the biopsy refused to do the procedure because they believed they weren't eligible for free NHS care. They told the GP [to] not refer them again until his immigration status was resolved. In their letter they said they were a 'drain on NHS resources'. (Legal immigration advisor)

It should be a clinical decision whether NHS treatment care is deemed to be urgent or immediately necessary, and if it is, it should be provided regardless of the patient's status or ability to pay upfront.

Participants shared examples of variation in people's understanding, interpretation, and attitudes toward this, meaning people with restricted or uncertain immigration status were treated differently by different staff, even within the same hospital.

> The response that we would get from some consultants was really empathic, and not short-sighted and they were quite understanding and sympathetic to what was going on for them in the community. . .there is one ward in particular that I'm thinking of with two different consultants and you knew that if one consultant was on, you were going to have to really argue for them to be kept on the ward whilst accommodation was sought for them. If the other consultant was on, you knew it wasn't going to be an issue. (Inclusion health hospital nurse)

Furthermore, participants in focus groups described a perception of intolerance toward people who were destitute, very unwell and with uncertain entitlements. This impatience focused on the difficulties faced in getting them discharged, rather than compassion for how they might need to be supported.

> There is greater haste around trying to discharge people, and also there's a measure that we're seeking to deal with, a measure of a kind of intolerance, really, or impatience with homeless people who can't be moved on as quickly. (Charity representative)

This variation may also be a result of or be reinforced by policies in force around charging for NHS care and about entitlements more generally. To begin to address this variation, focus groups' participants described how working across professional boundaries might improve access to support and better outcomes for people. This might involve influencing decisions around granting someone settled status, or challenging decisions about eligibility for support.

Fear, mistrust, and limited knowledge of the UK system

Late presentation to care services. Participants described how people with restricted or uncertain immigration status often presented to health services at a very late stage.

> People put off addressing health for maybe because they feel that they don't want to draw attention to themselves or they feel they're not entitled, so by the time that people are presenting it's really compounded. It's usually complex, there are multiple health conditions, and they're fairly advanced, so it's kind of rare that we're seeing people at the very earliest stages of their condition. It's all pretty chronic. (Inclusion health GP)

The reasons for this were varied. Fear and mistrust among some people in this situation toward the health and social care services, and the system in general were described as barriers to seeking support.

> We see a lot of people self-discharging because they are afraid. They are afraid of the system and they don't know what's going to happen to them, and what's next. It's a fear response. (Inclusion health nurse)

People were fearful of a range of things, from revealing their immigration status due to concerns about being discriminated against, treated poorly, becoming known to the system, or even being deported.

> Especially if they are seeking asylum, they may have had bad experiences with state bodies in their own countries and here as well. Their first contact here might have been police, or a heavy-handed immigration official. Hard to build trust. (Inclusion health GP)

Even when people were able to access services, they were sometimes concerned about disclosing personal information which might have repercussions for continuity of care and facilitating access to other services and supports.

> There's been issues with people having assumed someone else's identity and then they try to unpick it when the person finds out that they're dying, because all this stuff's been entered into the wrong medical record. One woman was using her sister's identity. Her sister was a British citizen. Her sister had just had a baby and she was dying from cancer, so we had to get her an NHS number and try to stop everyone from writing all this stuff in her sister's record. (Inclusion health GP)

Difficulty navigating systems. There was also a sense that the complexity of the benefits and welfare system in the United Kingdom meant that people were not sure what they were and were not entitled to. In addition, many people could not afford to take time off work to explore any health concerns, due to being on zero hours contracts or working cash in hand. This may have also led people to be fearful of being presented with large medical bills which they would be unlikely to ever be able to repay.

> There are people who know that they're ill but don't want to be asked to pay or don't think they're entitled, or you've just got that disengagement with authority, trying to stay under the radar thing, and I think there's the young men mainly who just work until they drop, and then the older people who just keep it quiet. (Day center worker)

Without support, navigating complex systems in a different language was seen as challenging.

> Lack of English language skills is a big issue. [If] they can't make themselves understood. . . even accessing somewhere like the day centers, where they could find someone to help them access a service, is challenging. We only see the tip of the iceberg. There will be many more people that we haven't heard about, those that aren't accessing the services that they need. (Homelessness staff)

We identified several issues around the use of interpreters. Face-to-face interpreters were reported to be expensive and so charities tend to use telephone interpreters. However, this was not consistently possible. Participants also noted a lack of specialism and choice among interpreters; the choice is often only a male or female interpreter. For example, interpreters specializing in medical interpretation were not always available. Although hospitals used in-person interpretation services, long wait times (often of days) meant that by the time the interpreter arrived, the person may have left.

Where treatment was obtained for people with uncertain or restricted immigration status, it was often the result of advocacy from staff. A 60-year-old respondent with sickle cell disease and with lived experience of homelessness and uncertain migration status, described how an outreach worker was supporting him to access support *via* his GP. Advocacy from his support worker meant that was able to receive treatment for his sickle cell disease.

> The sickle cell, you get pain in the joints, it troubled my head. The pain in the joints and so on. . . I don't feel any more sickle cell pain now. Sometimes when I sit on a chair for too long, it's sore but I don't like to sit down too long. (Person with lived experience)

Discussion

In the United Kingdom more than 1.4 million people have restricted eligibility for public funds and cannot rely on support from the state should they become unwell, unable to work, or experience financial hardship.^{25} Around one in five (18%) people with NRPF in the United Kingdom have experienced homelessness or insecure housing.[26]

This study is among the first to look at the barriers to palliative and end of life care access for people with uncertain or restricted immigration status, who have advanced health issues and who are experiencing homelessness. We spoke to a range of people from different professional backgrounds and worked hard to recruit people who were currently experiencing this situation.

The findings elucidate several barriers for people with uncertain or restricted immigration status who have advanced ill health and who are experiencing homelessness with regards to accessing the care and support they need. They demonstrate that current policies around NHS charging are costing lives, concurring with a report from the British Medical Association highlighting how charging is deterring vulnerable groups from accessing necessary healthcare.[3] Doctors of the World have also highlighted how these policies cause delays to treatment for people who are destitute but whose immigration status is uncertain.[11] In addition, despite no requirement for proof of address or ID to register with a GP practice, this is still being asked of people and acts as a barrier to accessing primary care. Resources have been developed to support heath professionals in addressing these barriers.[27]

In addition to issues around NHS charging policies, the thresholds for receiving accommodation and subsistence from local authorities for people with restricted immigration status are high and variable. Though local authorities may have a duty to provide support for people that have recognized care needs, regardless of their immigration status under the Care Act (2014)[28] our research has highlighted how local authorities are often surprised at being asked to use the Care Act for this purpose, and our respondents described situations where people with advanced illness and palliative diagnoses were found to be ineligible for support. This 'high bar' for support and lack of consistency in what constitutes a care need are major barriers to support. Without statutory guidance, it remains open to interpretation. As such, staff frequently spend large amounts of time advocating for support on their patient's behalf. The protracted decision-making processes evidenced here mean that people are being denied care due to a lack of suitable accommodation, resulting in devastating consequences. This variation in the responses of local authorities to supporting people with NRPF, and the delays that this causes are consistent with findings of prior research.[7,11]

Several factors preventing people with restricted or unsettled immigration status from accessing health care support until very late in their illness were also reported. These included previous negative experiences of health care services and subsequent mistrust, as well as more practical challenges such as understanding systems and booking or attending appointments. These issues have been highlighted in previous studies,[7,29–31] but not previously in relation to palliative and end-of-life care support for this population.

Implications for practice and future research

The findings from this study suggest, that where they are in place, joined up teams that consist of health, homelessness, and social care professionals seem to be valuable for navigating challenging and uncertain situations and advocating for access to support. Multi-professional teams also seem helpful for ensuring that everyone has the knowledge and support needed to advocate for access to support for people in this situation and those close to them. The need for multi-professional working has been recognized in guidance in the United Kingdom.[32] The support of likeminded colleagues is essential to maintain resolve and continue to advocate for patients despite the challenges that are faced.

In addition, easier access to immigration advice is essential in securing access to support for people with uncertain or restricted immigration status. These services have been severely cut in recent years.[5] Law centers and other charitable organizations operating in this field are an excellent source of advice and support and health care professionals should consider exploring those operating locally and nationally to support their advocacy for patients.

There is clearly a need for additional training around entitlements to benefit and support and around NHS charging within the health including palliative care, homelessness, and social care sector, in relation to accessing support for people with advanced ill health.[29,30] Training could include raising awareness that it is ultimately a clinician's decision whether NHS treatment can be given without charging upfront and include the need for care act assessments to consider circumstances beyond the hospital. There is an urgent need to raise awareness among palliative care professionals about entitlements and eligibility.

There is a need for more consistency about who is eligible for support under the Care Act. In addition, local authorities do have a power to provide support, including accommodation, even if someone is deemed not to reach the threshold under the Care Act. Cases described in this study, such as people with advanced cancer, could be supported in this way.

Good practice guidance to help councils in England provide a holistic response when an adult with NRPF is experiencing homelessness (supported by the UK Associated Directors of Children's Services) has been produced by the NRPF network in the United Kingdom.[33] If this guidance is enacted, there would be more consistency and more protection of the most vulnerable.

Limitations

The recruitment of people with current lived experience in this area was challenging. This may be related to a hesitancy toward participating in research studies, given what was described in both this and previous literature about not wanting to become known to systems or services. We attempted to recruit people with lived experience *via* professionals that were known to them; however, there will be many more people with restricted immigration status who may benefit from palliative and end-of-life care who were not known to professionals. Their experiences may differ from this sample. Future research would benefit from trying to expand the inclusion of the voices of people experiencing this combination of issues.

Conclusion

Fundamentally, current UK policies around supporting people with uncertain or restricted immigration entitlements are complex and create barriers to accessing care for people that need it. If we are truly committed to addressing inequity in health care access, we need to be more proactive at supporting people, regardless of their immigration status. There is a need for future research and policy work to challenge existing policies and practice that are perpetuating rather than addressing inequalities. There is a need for training around eligibility to support under the Care Act, as well as a recognition that local authorities also have a power to support people even if they do not reach a threshold for having care and support needs. In addition, there is a need for NHS clinicians to understand their role in determining whether treatment can be given in advance of payment for people who may not be entitled to free secondary care. In the meantime, there is a role for the hospice community to demonstrate that hospice and palliative care services are there to support everyone. Working alongside organizations that already support people with restricted immigration status, who are experiencing homelessness and whose health is poor would be a good first step at raising awareness of what palliative care is, who it can help, and how it is largely separate from the NHS in the United Kingdom. It is encouraging that the hospice community expresses a desire to widen their reach and support for those who previously may not have been accessing their services, now more than ever, we need to show that we mean it.

Declarations

Ethics approval and consent to participate

Ethical approval was obtained from University College London (ref: 6202/006). Informed consent was collected from all participants.

Consent for publication

Consent was obtained from all participants regarding publication of data shared, as part of the informed consent process.

Author contributions

Briony F. Hudson: Conceptualization; Data curation; Formal analysis; Funding acquisition; Investigation; Methodology; Resources; Supervision; Writing – original draft.

Elizabeth Dzeng: Conceptualization; Funding acquisition; Methodology; Writing – review & editing.

Angela Burnett: Conceptualization; Investigation; Methodology; Resources; Supervision; Writing – review & editing.

Michelle Yeung: Formal analysis; Writing – review & editing.

Caroline Shulman: Conceptualization; Data curation; Formal analysis; Funding acquisition; Investigation; Methodology; Supervision; Writing – original draft; Writing – review & editing.

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Competing interests

The authors declare that there is no conflict of interest.

Availability of data and materials

The survey and topic guides used in this research are available on request.

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